

**PERCEIVED SOCIAL SUPPORT, SYMPTOMS OF COMMON MENTAL
DISORDERS AND ADHERENCE LEVELS OF PATIENTS RECEIVING
ANTIRETROVIRAL TREATMENT**

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**Thesis presented in partial fulfillment of the requirements for the degree of Master of
Arts (Psychology) at the University of Stellenbosch.**



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DECLARATION

I, the undersigned, hereby declare that the work contained in this thesis consists of my own original work, and that I have not previously in its entirety or in part submitted it at any university for a degree.

Signed,

Adriaan Nel

A handwritten signature in black ink, appearing to be 'Adriaan Nel', written over a horizontal line.

ABSTRACT

Optimal adherence to antiretroviral medication is essential for effective treatment of the human immunodeficiency virus (HIV), and ensuring high levels of adherence has proven to be a major challenge in the fight against HIV. As funding for antiretroviral treatment (ART) programs is limited, ensuring optimal adherence is critical, not only to decrease patient mortality and improve quality of life, but also to make these ART programs financially sustainable. In recent years a small but growing body of literature on the associations between social support, common mental disorders and adherence to ART has emerged. This thesis builds on the burgeoning body of studies by seeking to test the associations between level of perceived social support, symptoms of common mental disorders, and adherence to ART among a South African sample of ART users.

The study investigated a convenience sample of 101 patients living with HIV, and receiving ART from a state funded HIV clinic in the Overberg region of the Western Cape, South Africa. A cross-sectional survey design was used to gather self-report data on the level of perceived social support, severity of symptoms of common mental disorders, and adherence to ART.

Bivariate correlations demonstrated significant negative associations between perceived social support and severity of symptoms of common mental disorders, specifically symptoms of depression, anxiety and posttraumatic stress disorder (PTSD). Biserial correlations and logistic regression analysis indicated an inverse relationship between severity of symptoms of depression and self-reported ART adherence. However, when symptoms of anxiety and PTSD were included as predictors, the association between symptoms of depression and self-reported ART adherence was no longer significant. Furthermore, no significant relationships were found between self-reported ART adherence and symptoms of anxiety and PTSD.

Follow-up research is recommended to gain a better understanding of these relationships. A longitudinal experimental research design is recommended to determine the direction of causality with regard to the association between symptoms of depression and adherence to ART.

OPSOMMING

Optimale nakoming van antiretrovirale medikasie is noodsaaklik vir effektiewe behandeling van die menslike immuuniteitsgebreks virus (MIV), en een van die groot uitdagings in die stryd teen MIV is om hoë vlakke van nakoming te verseker. Aangesien die beskikbare fondse vir antiretrovirale behandeling (ARB) beperk is, is dit van kritiese belang om optimale nakoming te verseker, nie net om sterftes te verminder en lewenskwaliteit te verbeter nie, maar ook om ARB programme finansieel volhoubaar te maak. In die afgelope jare, het daar 'n klein maar groeiende liggaam van literatuur oor die assosiasies tussen sosiale ondersteuning, algemene geestesversteurings, en nakoming van ARB na vore gekom. Hierdie proefskrif bou voort op die groeiende liggaam van studies deur om die verhoudings tussen waargenome sosiale ondersteuning, simptome van algemene geestesversteurings, en nakoming van ARB onder 'n Suid-Afrikaanse steekproef van ARB gebruikers te toets.

Die studie het ondersoek gedoen op 'n gerieflikheidsteekproef van 101 pasiënte wat MIV positief is, en ARB ontvang by 'n staats befondse MIV-kliniek in die Overberg-streek van die Wes-Kaap, Suid-Afrika. 'n Deursnee-opname ontwerp is gebruik om self-verslag data te kry oor die vlak van waargenome sosiale ondersteuning, simptome van algemene geestesversteurings, en nakoming van ARB.

Tweeveranderlike korrelasies het gedui op 'n beduidende negatiewe verhouding tussen waargenome sosiale ondersteuning and simptome van algemene geestesversteurings, spesifiek simptome van depressie, angst en post-traumatisiese stresversteuring (PTSS). Biseriale korrelasies and logistieke regressie-analise het 'n beduidende inverse verhouding tussen simptome van depressie and self-gerapporteerde ARB nakoming getoon. Die verhouding tussen simptome van depressie and self-gerapporteerde ARB nakoming was egter nie meer beduidend na die simptome van angst en PTSS as voorspellers ingesluit was nie.

Verder was daar geen beduidende verhoudings gevind tussen self-gerapporteerde ARB nakoming en simptome van angs en PTSS nie.

Verdere navorsing word aanbeveel om 'n beter begrip van hierdie verhoudings te verkry. 'n Longitudinale eksperimentele ontwerp word aanbeveel om vas te stel wat die rigting van oorsaaklikheid is ten opsigte van die verhouding tussen simptome van depressie en nakoming van ARB.

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CHAPTER ONE

Introduction

1.1 Human Immunodeficiency Virus

The human immunodeficiency virus (HIV) infects and destroys the body's CD4 cells, thereby weakening its ability to fight other opportunistic infections. If enough of these CD4 cells are destroyed, the weakened immune system leaves the body vulnerable to a variety of life threatening opportunistic infections, a condition known acquired immune deficiency syndrome (AIDS). According to the Joint United Nations Programme on HIV and AIDS (UNAIDS) and the World Health Organisation (WHO), an estimated 33.4 million people worldwide were living with HIV in 2008 (UNAIDS, 2009). During this time, the annual amount of worldwide new HIV infections was estimated at around 2.7 million, with about 2 million AIDS related deaths per year. Sub-Saharan Africa accounts for the largest proportion of the epidemic, with around 22.4 million people living with HIV. In 2008, an estimated 1.9 million people living in sub-Saharan Africa were infected with HIV, and approximately 1.4 million people in this region died from AIDS related illnesses (UNAIDS, 2009).

To date, there is no vaccine to prevent infection of HIV, and no cure once infection has occurred. However, HIV progression can be managed, through the administration of antiretroviral therapy (ART). ART involves providing a patient with a cocktail of drugs, known as antiretrovirals, or ARVs, which prevents the HIV virus from replicating itself within the body, effectively slowing the growth of the virus. ART has been shown to reduce the amount of virus, or viral load, within the blood, and also to increase the body's CD4 cell count (Li et al., 1998). Ultimately, successful ART can result in increased life expectancy (Olalla et al., 2002) and improved quality of life (Mannheimer et al., 2005).

1.2 Importance of Adherence to ART

In order for ART to be successful, however, it is essential that the patient adheres to his or her treatment regimen (Olalla et al., 2002; Sethi, Celentano, Gange, Moore & Gallant, 2003). Failure to adhere to the treatment regimen can result in decreased CD4 count, increased viral load, poor quality of life, and mortality (Olalla et al., 2002; Sethi et al., 2003; Mannheimer et al., 2005). Moreover, once ART has been initiated, failure to adhere to the treatment regimen can cause the virus to develop resistant strains, which typically require treatment with more expensive second line ARVs in order to be suppressed. Ensuring optimal adherence to ART has proven to be one of the major challenges facing the sub-Saharan Africa HIV response, and the WHO (2009) has recently reemphasised adherence to ART as one of four priority research areas within the field of HIV and AIDS.

In recent years, a considerable amount of research has been done on factors that influence ART adherence among people living with HIV. A wide range of factors have been identified, among which are health literacy, level of income, stigma, mental health, perceived social support and various logistic and institutional barriers (Kagee, 2008). The present study will focus on two of these areas, namely mental health and perceived social support. Specifically, the role and importance of common mental disorders and perceived social support within the context of ART adherence will be discussed.

1.3 Rationale for Present Study

Despite an increase in research outputs on barriers to ART adherence, there is a need for more research within this field (Kagee, 2008), particularly with regard to patient characteristics. Specifically, there is a paucity of South African research on the role of common mental disorders in influencing adherence, as well as the role of social support in influencing this relationship. Virtually no South African studies have investigated models that

simultaneously include relationships between common mental disorders, social support and ART adherence. It is hoped that the present study will in part address this gap in the literature.

1.4 Study Aims

The present study aims to investigate the relationships between severity of symptoms of common mental disorders, level of perceived social support, and adherence to ART. The specific aims are as follows:

1. To determine the severity of symptoms of common mental disorders among patients receiving ART at the Helderberg Hospital Infectious Diseases Clinic.
2. To investigate the relationship between common mental disorders and adherence to ART among patients receiving ART at the Helderberg Hospital Infectious Diseases Clinic.
3. To investigate the relationship between level of perceived social support and adherence to ART among patients receiving ART at the Helderberg Hospital Infectious Diseases Clinic.

1.5 Study Hypotheses

The present study proposed three hypotheses:

H₁ - Severity of symptoms of common mental disorders is negatively correlated with ART adherence.

H₁ - Level of perceived social support has a positive correlation with ART adherence.

H₁ - Level of perceived social support is negatively correlation with severity of symptoms of common mental disorders.

The three null hypotheses are as follows:

H_0 - There is no association between severity of symptoms of common mental disorders and ART adherence.

H_0 - There is no association between level of perceived social support and ART adherence.

H_0 - There is no association between level of perceived social support and severity of symptoms of common mental disorders.

1.6 Outline of Thesis

Following from the above introduction, Chapter 2 will provide a brief introduction to ART, and factors influencing ART. These factors influencing ART will be discussed from within the ecological systems conceptual framework as proposed by Bronfenbrenner (1979). Among these factors influencing ART, particular emphasis is placed on social support, with regard to its respective direct and indirect effects on ART adherence. Similarly, an in depth discussion of common mental disorders as potential barriers to ART adherence will be given, in terms of the theoretical grounds on which these relationships are assumed and the empirical findings supporting the theory. Chapter 3 provides an overview of the methodology used to investigate the associations between severity of symptoms of common mental disorders, level of perceived social support, and self-reported adherence to ART. In Chapter 4, results from the data analysis are presented. Following from Chapter 4, Chapter 5 provides a discussion of the results, along with the relevant limitations and recommendations.

CHAPTER 2

Literature Review

2.1 Introduction

Optimal ART adherence is essential for effective treatment of HIV (Olalla et al., 2002; Sethi et al., 2003), and ensuring optimal adherence to ART has proven to be a major challenge in the fight against HIV and AIDS (Rosen, Fox, & Gill, 2007; WHO, 2009). This chapter examines the literature on ART adherence and some of the patient characteristics that can influence ART adherence. The importance of ART adherence will be explained, along with possible barriers to ART adherence. These possible barriers are contextualised within an ecological systems perspective. The discussion of factors associated with adherence includes an in depth review of the role of social support and common mental disorders in influencing adherence to ART.

2.2 Importance of ART Adherence

According to the WHO, an estimated 4 million people were enrolled in ART programs in low- and middle-income countries across the world in 2008, roughly 1 million more than in 2007 (WHO, 2009). Efforts to improve coverage in low- and middle-income countries have been successful with an approximate increase from 33% to 42% between 2007 and 2008 (WHO, 2009). However, there is a growing body of evidence suggesting that retention in ART care and adherence to pill-taking in the context of antiretroviral programmes administered by public health systems are sub-optimal, with negative effects experienced by patients, their families, and society in general (Rosen et al., 2007; WHO, 2009). Sub-optimal adherence in ART programs continues to pose a threat to successful treatment outcomes, especially during the first year of treatment (Rosen et al., 2007; WHO, 2009).

Consequences of sub-optimal adherence include lower CD4 count, higher viral load, mortality, and poor quality of life (Mannheimer et al., 2005). Furthermore, once ART has been initiated, failure to adhere optimally increases patients' risk of developing resistant strains of HIV, requiring the use of more expensive second line antiretrovirals (WHO, 2007). As funding for ART programs is limited, ensuring optimal adherence becomes essential, not only to decrease patient mortality and improve quality of life, but also to make these programs financially sustainable.

2.3 An Ecological Systems Perspective on Adherence

For the purposes of this investigation, Bronfenbrenner's (1979) ecological systems perspective was used to provide a framework for the various factors influencing adherence, and the different systems within which they operate. Bronfenbrenner identifies four levels of interaction, or systems, which can be used to describe and understand an individual's behaviour and development, namely the microsystem, mesosystem, exosystem, and macrosystem.

Any given individual can be seen as being linked to various microsystems. This involves a person's direct experiences and interactions with other individuals, such as family, friends, or professional acquaintances, as well as settings and organisations such as a church, clinic, sports venue, academic institution, or the individual's workplace.

The mesosystem refers to the links the different contexts or microsystems. For example, if a person is involved with both a college and a church, the linkages between said college and church can be referred to as a mesosystem. According to Bronfenbrenner (1979), such a person's development can be enhanced if these settings have similar values and if there is goal consensus between these settings.

Contexts to which an individual is not directly linked, but that impact the individual's experiences, are referred to as exosystems. In other words, it refers to connections between an individual's microsystems and other systems that the individual is not directly involved with. For example, the community clinic where an individual receives treatment may be linked to a healthcare committee responsible for governing policy in the clinic. If the healthcare committee were to change policy within the clinic, it could indirectly affect the individual's experiences, even though the individual does not have any direct links to the committee.

The macrosystem is defined as the wider system of organisation and ideology of social contexts and institutions that are specific to the individual's culture, ethnic group, gender, and socioeconomic position in society (Bronfenbrenner, 1979). In essence, it describes the way in which an individual's experiences are influenced by ideology linked to the various demographic characteristics that forms part of his or her identity.

Bronfenbrenner's (1979) presents the ecological systems framework primarily from within a developmental psychology point of view. In the present investigation, however, it is used simply to contextualise potential barriers to adherence. In the discussion below, an ecological systems perspective is used to present a framework for the literature on factors influencing adherence. It should be mentioned, that some of the factors influencing adherence, can be seen as operating in more than one system of the ecological model. With this limitation in mind, each factor influencing adherence is discussed within the system that it is most closely associated with. In some cases, a given factor is discussed within more than one system, depending on the manner in which it influences adherence.

2.4 Factors Influencing Adherence on a Macrosystem Level

On a macrosystems level, societal attitudes and beliefs regarding an HIV positive status could influence the beliefs and actions of those living with HIV. Depending on the

group (culture, class, gender etc.) that an individual belongs to, an individual's or patient's behaviour could be governed in ways that either promotes or negatively impacts adherence, depending on the group's organisation and the ideology that is common to members of the group. With this in mind, stigma surrounding HIV and beliefs regarding ART are discussed as factors that can influence adherence on a macrosystems level.

2.4.1 Stigma and discrimination.

Stigma and discrimination have been identified as barriers that can undermine adherence to ART (Kagee et al., 2010; Rintamaki, Davis, Skripkauskas, Bennett & Wolf, 2006)). If a person living with HIV is seen to be taking ART or attending an HIV clinic, it may serve as an indicator that he or she is HIV positive (Kagee et al., 2010). Even in settings where access to ART is readily available, those living with HIV may not be willing to obtain and/or take ARV medication in situations where they may be seen by family, friends, and other community members, out of fear of being ostracised (Rao, Kekwaletswe, Hosek, Martinez & Rodriguez, 2007; Rintamaki et al., 2006). In these cases where patients are not willing to take medication out of fear that their family and friends will discover their HIV positive status (e.g. Rao et al., 2007), it has the added disadvantage of eliminating family and friends as a source of social support, resulting in a missed opportunity in terms of assisting them with adherence and aiding these individuals to overcome potential barriers to adherence.

2.4.2 Beliefs about ART.

The knowledge and beliefs that a patient has about his or her disease, and also about the medication for the disease, can influence medication adherence (WHO, 2003). A thorough understanding of the association between adherence and viral load, as well as the

association between viral load and HIV disease progression, has been found to be integral in ensuring good adherence among patients receiving ART (Chesney, Ickovics, et al., 2000). In addition, adherence levels have been demonstrated to be higher among patients who believed that ART would be effective (Wenger et al., 1999). Similarly, negative beliefs about ART are associated with lower motivation to adhere to the medication regimen (Siegel, Karus & Schrimshaw, 2000).

2.5 Factors Influencing Adherence on an Exosystem Level

With regard to exosystems, the focus is on systems, policies, organisations and institutions with which individuals receiving ART may not be directly involved with, even though these organisations can substantially influence such individuals' likelihood to access and adhere to treatment. The discussion below considers the potential influence of political context on adherence to ART. In addition, since medication regimens are informed by research, development, and policy, medication regimens are also discussed in terms of their impact on adherence.

2.5.1 Political context and ART.

South Africa has a history of AIDS denialism, wherein the former Minister of Health posited unproved remedies for the treatment of HIV (Kagee et al., 2010), and created confusion among the public regarding HIV and AIDS. Such situations can make it difficult for proven ART programmes to ensure adherence among patients, as patient knowledge about HIV plays an important role in ensuring optimal adherence (Chesney, Ickovics, et al., 2000), and patients' beliefs about the effectiveness of ART can influence their adherence levels (Siegel et al., 2000; Wenger et al., 1999). In addition, adherence to ART is only possible if both governmental and non-governmental organisations are committed to securing

funding for ART and ensuring an uninterrupted supply of ARVs. Failing to do this, creates a structural barrier to adherence, leaving those in need of ART without treatment, and in some cases leaving those already initiated on ART without treatment (UNAIDS, 2009; WHO, 2009).

Likewise, the administration and organisation of any nationwide ARV rollout could affect the willingness of patients to participate in treatment. A system that is well staffed, well funded, and well organised allows for clinics that can provide high quality care (WHO, 2009). In other words, clinics that can respond to patient needs, that provide all the necessary information, that ensures short waiting times, and that generally creates a safe and low stress environment for patients to receive treatment. The aforementioned favourable clinic conditions make it easier for patients to adhere to their ART programmes (WHO, 2009).

2.5.2 Medication regimen.

Research and development surrounding ARVs can substantially alter the likelihood of adherence, especially in terms of regimen characteristics. The literature shows that for many chronic diseases, the likelihood of adherence decreases as the complexity of the regimen increases (Chesney, Morin & Sherr, 2000; Greenberg, 1984). The regimen complexity in this context refers to the number and type of pills that must be taken per dose, the number of doses per day, and dietary instructions and restrictions that form part of the treatment regimen. In the case of ART medication adherence, the patient not only has to learn how to adhere to a complicated medication regimen, but also has to adjust his or her daily schedule to accommodate the regimen. This can be even more difficult if the regimen requires the patient to make frequent visits to healthcare facilities. Some studies have demonstrated that fewer pills and lower doses make it easier for patients to fit the medication regimen into their

daily schedules, which ultimately makes it easier for them to adhere to their medication (Chesney, Morin & Sherr, 2000; Greenberg, 1984).

In addition to the regimen complexity, the medication's associated side effects can play a vital role in whether a patient is adherent or not. Optimal adherence is most common in cases where the medication removes symptoms, while adherence has been shown to be lower for medications that cause side effects (Chesney, Ickovics, et al., 2000; Chesney, 2000). Therefore in terms of regimen characteristics, both the regimen complexity and the associated side effects have been identified as key factors influencing adherence. Specifically, it has been suggested that regimens that require severe lifestyle changes in addition to producing side effects may result in treatment fatigue and frustration on the part of the patient, thereby increasing the risk of noncompliance (Halkitis, Parsons, Wolitski & Remien, 2003).

2.6 Factors Influencing Adherence on a Mesosystem Level

At the mesosystems level, the links between the various contexts in which patients receiving ART are involved are investigated in terms of their impact on adherence to ART. Specifically, the most prominent financial barriers are investigated. In addition, the role of traditional healers with regard to adherence is discussed.

2.6.1 Financial barriers to ART.

The literature suggests that the mesosystem could be closely associated with poverty-related barriers (Coetzee, Kagee & Vermeulen, 2011). There are a number of structural issues that are associated with poverty, and that can potentially undermine adherence.

2.6.1.1 Clinic visits and access to transport.

Depending on the distance between the individual's residence and the clinic, access to transport could be necessary to make clinic visits possible, or simply to make it more convenient. Low- and middle income countries are often characterised by poor infrastructure and inadequate transport (Kagee et al., 2010). In some cases, patients in public health clinics do not have private transport, and have to rely on public transport, which can be expensive, unsafe, and in some cases unavailable (Kagee, Le Roux & Dick, 2007). As a result, patients living far from clinics often have to walk, potentially requiring substantial effort, especially for patients that are feeling unwell (Kagee et al., 2010).

2.6.1.2 Food insecurity

In cases where poverty leads to food insecurity, situations can arise wherein patients enrolled in ART programmes may experience problems with adherence as a consequence of food insecurity. In a qualitative study conducted among patients living with HIV in three low income countries, respondents reported being unable to afford the additional food needed to regain the strength lost during the early stages of ART (Hardon et al., 2007). The food insecurity created a problem with regard to adherence, as some patients indicated that they only took their medication when they had food available.

2.6.1.3 Problems associated with resource constrained contexts.

Patients living in low income areas may face a number of issues related to poverty, including unemployment, inadequate housing, community violence and forced migration (Kagee et al., 2010). In these cases, patients may prioritise other needs over that of adhering to ART. Moreover, life stress is more common and more severe among individuals of low socioeconomic status, and is said to reduce the likelihood of adherence among these

individuals. (WHO, 2003) Lastly, adherence appears to be more difficult for patients with lower levels of education and literacy (Stone, 2001).

2.6.2 Traditional healers and ART.

The presence of traditional healers in South Africa is substantial and considerably larger than that of doctors practicing modern medicine (Kale, 1995). In several areas patients may prefer to obtain HIV treatment from traditional healers, and as a result traditional healers constitute an extensive network that can work together with modern healthcare practitioners to create additional access points for HIV care (Homsy, King, Balaba & Kabatesi, 2004). In this regard, it has been suggested that traditional healers can collaborate with primary healthcare providers (Wilkinson, Gcabashe & Lurie, 2001). Moreover, it has been suggested that traditional healing practices can compliment that of modern medicine (Wilkinson et al., 2001), and potentially assist ART adherence among patients living with HIV (Homsy et al., 2004; Kagee et al., 2010). On the other hand, if traditional healing practices are not integrated with ART care, it can undermine adherence by creating uncertainty about ART among patients (Kagee et al., 2010), and by creating competition for ART programmes (Lubega et al., 2010). In Uganda, traditional healers undermined adherence to pre-ARV care by providing competing services that was perceived as being more effective by HIV patients, resulting in some dropping out from pre-ARV care (Lubega et al., 2010).

From within a mesosystems perspective, this can be seen as the difference between contexts where values, beliefs and practices are similar, versus contexts where values, beliefs, and practices are contradictory. If a traditional healer's beliefs and practices correspond with that of the public health clinic, and promotes adherence to ARV medication, it could motivate the patient and make it easier for him or her to be adherent to treatment. If, on the other hand, the traditional healer's values contradict the values of the clinic, perhaps discouraging the use

of medication to treat HIV, it could dissuade the patient from adhering to treatment. In this sense, adherence should be easier for those whose treatment settings are linked to their other settings in terms of values, beliefs, practices and goals.

2.7 Factors Influencing Adherence on a Microsystem Level

There are a number of microsystems that could allow, assist and promote adherence, while in some cases, there may be some that undermine it. Those discussed as acting within mesosystems, including the financial barriers, can also be seen as functioning at a microsystems level. In addition, the relationship between the provider and patient, and the influence of social support received by patients living with HIV are discussed here.

2.7.1 The relationship between the provider and patient.

A good relationship between a healthcare provider and patient is associated with improved adherence to ART (Chesney, 2000; WHO, 2003). In a study by Beach, Keruly and Moore (2006), patients who reported that their provider knew them “as a person” were significantly ($p < .01$) more likely to be adherent to their ART. If the relationship between the provider and patient is characterised by clear communication, compassion, active involvement of the patient in treatment decisions, and perceptions of provider competence, the patient will be more likely to be adherent to the medication regimen (Chesney, 2000). On the other hand, if the provider is not sensitive to the patient’s needs, or communication between provider and patient is poor, this can result in frustration on the part of the patient, ultimately leading to poor adherence (WHO, 2003).

2.7.2 Social support.

At microsystems level, social support may influence adherence in a number of ways, as family, friends and community members can provide both emotional and tangible support. Conversely, poor sources of social support could work against adherence. The discussion below gives an in depth overview of social support as a factor influencing adherence.

2.7.2.1 The relationship between social support and adherence.

The degree to which a patient can adhere to a given medication regimen and cope with potential mental health problems, is to some extent dependent on the patient's level and quality of social support. The literature suggests that social support can be a protective factor which not only allows for better adherence (Davies et al., 2006; Holstad, Pace, De, & Ura, 2006; Parruti et al., 2006), but also improves the patient's ability to cope with stressful life events (Singh et al., 1999). Positive social support, such as having a supportive family, being in a stable intimate relationship, or being married, appears to be strongly associated with adherence to ART (e.g. Davies et al., 2006; Holstad, Pace, De, & Ura, 2006; Parruti et al., 2006). It has been shown that friends and family expressing concern and support regarding a patient's engagement in health promoting behaviours, including adherence to medication, could work together with the patient's social desirability needs to improve the patient's ART adherence (Kagee, 2008). In addition, tangible support could help sustain adherence by for example providing financial assistance, helping with transport for clinic visits, or assisting the patient in meeting dietary requirements (Singh et al., 1999). Conversely, it has been shown that a disruption in positive social support such as family conflict, the end of an intimate relationship, or the death of a spouse may cause some patients to question the need to adhere to their medication (Wood, Tobias, & McCree, 2004). Furthermore, the stigma associated

with a positive HIV status could discourage patients from seeking and attaining the necessary social support, making it more difficult for them to adhere to ART (Rintamaki et al., 2006).

It has been suggested that social support can influence adherence directly, by providing reminders and reinforcements, or indirectly, by mitigating the negative events of other stressful events (Singh et al., 1999). Also, it is argued here that social support not only mitigates stressful life events, but also the severity of symptoms of common mental disorders, which in due course results in improved adherence to ART. There is, however, still very little research investigating the manner in which social support can indirectly influence ART adherence, by influencing the common mental disorders that are associated with ART adherence. Following from the previous sections suggesting a negative association between common mental disorders and ART, the following section examines the association between social support and common mental disorders.

2.7.2.2 Social support, common mental disorders and adherence.

It has been argued that social support can buffer the effects of stressful life events, according to a theory known as the buffering hypothesis, or the stress-buffering model (Cohen & Thomas, 1985). Cohen and Thomas (1985) distinguish between three categories of social support, namely tangible support, emotional support, and appraisal support. Tangible support involves material support that is perceived, by the receiver, as relevant and appropriate for the particular situation. Emotional support refers to support that influences the receiver's evaluations and feelings about themselves. Appraisal support, on the other hand, influences the receiver's view of external situations, such as a potential stressor. Cohen and Thomas (1985) argue that each of these categories of social support can improve an individual's ability to cope with stressful life events. It is also proposed that ultimately, social support can mitigate symptoms of psychopathology, and potentially prevent the onset of a

psychopathological outcome. Psychopathology, as used by Cohen and Thomas (1985), includes common mental disorders, such as depression.

In addition to the abovementioned stress-buffering model, another model is proposed, which is known as the main effect model (Cohen & Thomas, 1985). According to the main effect model, social support leads to health promoting behaviours, which in turn leads to improvements in mental health. In contrast to the stress-buffering model, the main effect model can explain improved mental health in the absence of stress. The stress-buffering model and the main effect model are not necessarily mutually exclusive, as these two models can be used simultaneously to explain the association between social support and mental health. For the purposes of this review, the term “buffer” will be used for both of these models, as both of these models ultimately explain an inverse relationship between social support and symptoms of common mental disorders.

The abovementioned buffering theories are supported by a number of empirical studies investigating various populations. In a review of various studies published in the period between 1970 and 2000, Kawachi and Berkman (2001) concluded that there is a well established positive association between social support and mental health. Subsequent to the review by Kawachi and Berkman (2001), a number of more recent publications have demonstrated a fairly consistent inverse relationship between social support and common mental disorders (e.g. Cruza-Guet, Spokane, Caskie, Brown & Szapocznik, 2008; Dalgard et al., 2006; Dobkin, De Civita, Paraherakis & Gill, 2002; Maulik, Eaton & Bradshaw, 2010; Serovich, Kimberly, Mosack & Lewis, 2001; Takizawa et al., 2006; Wildes, Harkness & Simons, 2002) in various populations. In these studies, the exact manner in which social support acts as a barrier to both the negative life events responsible for causing mental disorders and the mental disorders themselves varies depending on the sample and geographical context in which the study is conducted. For example, among 4,558 middle

aged (40-69 years of age) individuals residing in Japan, high levels of social support was shown to effectively buffer depressive symptoms in males, but not in females (Takizawa et al., 2006). In contrast, in a sample of 8,832 respondents between the ages 18 of 64 years, randomly selected from Finland, England, Ireland, Spain and Norway, the association between low levels of social support and depression was stronger for females than for males (Dalgard et al., 2006).

Another factor involved in explaining the strength of associations between social support and mental disorders is the type of social support provided, and how this type of support is defined and measured. For example, among 273 elders (70-100 years of age) living in the United States, self-report scales were used to measure psychological distress (symptoms of anxiety and depression), received social support, and satisfaction with received social support (Cruza-Guet et al., 2008). Results indicated that while satisfaction with received social support was associated with lower psychological distress, the reported level of received social support was associated with higher psychological distress.

With regard to all the empirical studies investigating the relationship between social support and common mental disorders cited above, there appears to be considerable variation in terms of the type of social support that is investigated, the definition and method used to investigate the selected type of social support, the geographical context of the study, and the demographic characteristics of the population under investigation. Critically, study findings varied based on these factors. It therefore becomes problematic to generalise these findings across populations. That being said, most of the studies reviewed by Kawachi and Berkman (2001), and all of the studies cited here (e.g. Cruza-Guet et al., 2008; Dalgard et al., 2006; Dobkin et al., 2002; Maulik et al., 2010; Serovich et al., 2001; Takizawa et al., 2006; Wildes et al., 2002) indicate some form of inverse relationship between the level of social support and symptoms of mental disorders.

There are virtually no empirical studies examining the relationship between social support and mental disorders among people living with HIV in South Africa. One publication, by Freeman, Nkomo, Kafaar and Kelly (2007), investigated factors associated with mental disorders among people living with HIV in South Africa. Among the 900 respondents, those being isolated as a result of their positive HIV status were significantly more likely to have a diagnosable mental disorder, compared to respondents who did not report isolation as a result of HIV status. In addition, discrimination as a result of a positive HIV status significantly predicted the presence of a mental disorder.

2.7.2.3 Social support as protective factor for adherence.

Based on the above discussion, it appears as if positive social support can often have a constructive impact on adherence, both directly by providing emotional and tangible assistance and indirectly by mitigating potential barriers to adherence, including life stress and mental health problems. To summarise, social support could help a patient to adjust to the life stress associated with living with HIV and receiving ART, mitigate potential barriers to adherence, motivate the patient to adhere to treatment, and provide tangible assistance to facilitate adherence.

2.8 Factors Influencing Adherence at Individual Level

Finally, there are a number of individual level factors that could influence a patient's ability to adhere to treatment. These include the patient's knowledge about HIV and ART, as well as potential mental health problems. These factors are discussed below, with specific emphasis on how the patient's ability to cope with life stress, mental health problems (including depression and anxiety), use of drugs and alcohol, and health habits can influence adherence.

2.8.1 Patient knowledge about HIV and ART.

With regard to knowledge, both confusion and forgetfulness have been identified as major obstacles in ensuring effective adherence (WHO, 2003). A number of studies have reported that the most patients cited forgetfulness as the main reason for failing to adhere to their medication (Ostrop, Hallett & Gill, 2000; Chesney, Morin & Sherr, 2000; Murphy, Wilson, Durako, Muenz & Belzer, 2001). Also, in one study, individuals with poorer adherence reported significantly greater confusion regarding regimen instructions, than those with optimal adherence (Catz, Kelly, Bogart, Benotsch & McAuliffe, 2000).

2.8.2 Mental health problems and adherence.

Several studies have investigated common mental disorders among people living with HIV, in most cases either to determine prevalence or to establish its effect on treatment and care. Among studies investigating psychological distress and mental disorders in HIV populations, psychological distress is most commonly manifested in symptoms of depression and anxiety (e.g. Ammasari et al., 2004; Campos et al., 2008; Gordillo et al., 1999; Myer et al., 2008; Kagee & Martin, 2010). Disorders related to substance abuse and alcohol abuse are less common in the literature, but have also been found to be prevalent in some HIV populations, especially in sub-Saharan Africa (Brandt, 2009; Freeman, Nkomo, Kafaar & Kelly, 2008). The rate of mental disorders is substantially higher among people living with HIV, in comparison to HIV negative people from similar demographic backgrounds (Freeman et al., 2008). The following section provides an overview of common mental disorders and symptoms of common mental disorders acting as barriers to optimal ART adherence.

2.8.2.1 Depression.

Depression has been identified as one of the most important mental health-related barriers to ART adherence (Alfonso, Geller, Bermbach, Drummond, & Montaner, 2006). A recent systematic review of 27 studies of mental health problems among persons living with HIV in Africa showed that the prevalence of clinical depression ranged from 20% to 35% (Brandt, 2009). In South Africa, Freeman et al. (2008) conducted a comprehensive study using diagnostic interviews on 900 participants over 18 recruitment sites, to determine the prevalence of common mental disorders among people living with HIV. Among this sample, the prevalence rates were 11.1% for major depression, and 29.9% for minor depression (Freeman et al., 2008).

The symptom picture for depression includes low motivation, poor concentration, sleep disturbance, psychomotor retardation, fatigue or loss of energy, and feelings of worthlessness (APA, 2000), all of which have potential adverse implications for medication adherence. Specifically, some depressed persons may be unlikely to have adequate motivation and self-efficacy to attend clinic appointments and take their medication with the required regularity. Persons experiencing feelings of hopelessness could have reduced motivation to care for themselves, and may have reduced ability to follow the complex instructions associated with an ART medication regimen (WHO, 2003).

Studies investigating adherence have demonstrated an inverse relationship between severity of depression and ART adherence (Gordillo et al., 1999; Ammasari et al., 2004; Campos et al., 2008). In some cases patients receiving ART who exhibit symptoms of depression are up to three times more likely to be non-adherent to their medication regimens than their non-depressed counterparts (Ammasari et al., 2004). Relatedly, depression has also been shown to indirectly reduce patients' ART adherence, by influencing medication adherence self-efficacy (Reynolds et al., 2004). In the study by Reynolds et al. (2004),

depression was associated with less certainty about the potential effectiveness of ART and consequently the perceived ability to adhere to ART. Ultimately, a reduction in adherence self-efficacy was associated with a reduction in adherence to ART.

It should be noted that when mental health treatment is available, patients suffering from a diagnosable psychiatric disorder have been found to be more likely to be adherent to ART (Himelhoch et al., 2009). In the aforementioned study, 4989 patients were investigated over a period of 5 years. Among this sample, 24.8% of the participants were diagnosed with depressive disorders and 9% were diagnosed with serious mental illness (schizophrenia spectrum disorders and bipolar disorders). Analysis revealed that during the first year of ART, the probability of discontinuing ART for both the depressive disorders group and the serious mental illness group was significantly lower compared to the group without diagnosable mental disorders. This finding, however, was only true for patients attending more than five mental health visits per year. Therefore, it seems that in the absence of mental health treatment, depression acts as a barrier to adherence.

2.8.2.2 Anxiety disorders.

For the purposes of this review, a distinction will be made between anxiety and posttraumatic stress disorder (PTSD). Among the studies discussed in this section, those screening for symptoms of anxiety predominantly used brief self-report scales screening for symptoms of the two anxiety disorders that are most prevalent within the general population, namely generalised anxiety disorder and panic disorder (Sadock & Sadock, 2007). By contrast, the studies screening for symptoms of PTSD explicitly stated that PTSD was under investigation.

In the discussion below, the term “anxiety” will be used as a joint term for symptoms of generalised anxiety disorder and panic disorder, while the term “PTSD” will be used only

for symptoms of PTSD. As will be discussed below, it appears as if the association between anxiety and ART adherence differs from the association between PTSD and ART adherence.

2.8.2.2.1 *Anxiety.*

The symptom picture for generalised anxiety disorder includes impairment in concentration, which is essential for schedule, dose, and dietary adherence (Sadock & Sadock, 2007). Patients with elevated levels of anxiety may have an impaired ability to concentrate on the preparatory tasks associated with taking their medication, such as filling prescriptions, keeping their medication with them, remembering to take the medication on time, and remembering the correct dosages.

The symptom picture for panic disorder, on the other hand, does not include impairment in concentration. However, the intense physical symptoms associated with panic disorder, such as feeling dizzy, lightheaded or faint, experiencing derealisation or depersonalisation, persistent fear and worry related to attacks, and so on (Sadock & Sadock, 2007), could interfere with the cognitive processes involved in medication adherence.

In the review by Brandt (2009) it was found that between 19% and 37% of persons living with HIV in Africa exhibited elevated levels of anxiety-related symptoms. There is some empirical evidence suggesting that anxiety acts as a barrier to adherence, as longitudinal data have shown that severe anxiety predicts non-adherence to ART (Campos et al., 2008). Anxiety may also reduce adherence indirectly by affecting self-efficacy, as perceived stress is associated with more uncertainty regarding adherence self-efficacy (Reynolds et al., 2004).

2.8.2.2.2 PTSD.

While the relationships between anxiety and adherence appear relatively straightforward, the influence of PTSD-related symptoms on ART adherence is more complex. Delahanty, Bogart and Figler (2004) have shown a negative relationship between symptoms of PTSD and ART adherence. Yet, other data contradict this conclusion. Specifically, in a study of 193 Swedish patients receiving ART, Schönnesson, Williams, Ross, Bratt, and Keel (2006) found that persons who displayed HIV-related PTSD symptoms were significantly more likely to report a high level of schedule adherence (OR = 0.316, 95% CI = 0.146-0.683). These authors attribute this relationship to the likelihood that PTSD symptoms may result in patients experiencing self-protective alertness and vigilance concerning their health, and thus engage in more adherent behaviour. They also consider the possibility that HIV-related PTSD symptoms may occur as a result of being adherent to schedule, as concerns about failing to adhere provoke profound anxiety about developing drug resistance and HIV-related illness. Schönnesson et al. (2006) suggests that psychopathological symptoms, or in this case symptoms of PTSD, lie on a spectrum from disabling distress to health-protective concern.

It has been suggested that the effects of depression should be included or controlled for in any analysis investigating the relationship between PTSD and ART adherence (Vranceanu et al., 2008). This is because, in some cases, the primary cause of suboptimal adherence may not be PTSD, but rather the presence of a co morbid depressive disorder (Vranceanu et al., 2008). Furthermore, the combined effect of PTSD and depression can have on adherence could be more severe than the effect of either disorder in isolation (Boarts, Sledjeski, Bogart & Delahanty, 2006).

2.8.2.3 Alcohol and substance abuse.

It is estimated that between 7% and 16% of persons living with HIV in Africa either abuse or are dependent on alcohol and other substances (Brandt, 2009). In the South African sample investigated by Freeman et al. (2008), the prevalence of alcohol abuse disorder was 12.4% (Freeman et al., 2008). While alcohol and substance abuse have been shown to be comorbid with other mental disorders (Compton, Cottler, Ben-Abdallah, Cunningham-Williams & Spitznagel, 2000), it is likely to influence adherence in its own right. Persons who are regularly intoxicated usually have impairments in areas such as memory, concentration, and physical coordination (Nevid, Rathus & Greene, 2006).

A review by Hendershot et al. (2009) examines the relationship between alcohol use and adherence to ART. The authors selected 100 studies for full review, of which 40 were selected to be included in a meta-analysis. Publication dates for the 40 qualifying studies spanned from 1998 to 2007, with a combined sample size that exceeded 25,000. Effect sizes suggested that participants that used alcohol were between 50% and 60% as likely to be classified as adherent to ART, compared to those that did not use alcohol, or used a relatively low amount of alcohol.

A study investigating substance abuse and ART among a sample of 659 patients living with HIV, found that patients using illicit drugs or abusing other substances are significantly ($p < .01$) less adherent than those that have never abused substances (Hicks et al., 2007). Moreover, the authors found that former substance users receiving substance abuse treatment were more likely to be adherent in comparison to those not receiving substance abuse treatment. Subsequent studies have found results similar to that of Hicks et al. (2007), and supports the notion that substance abuse does act as a barrier to ART adherence, and that substance abuse treatment can improve adherence to ART (Kapadia et al., 2008; Mellins et al., 2009).

In addition to its effect on ART, alcohol and substance abuse also influence patients' social relationships, as intoxicated patients risk negative interactions with healthcare workers during clinic visits, who may feel that the patient is compromising the potential treatment benefits (Kagee & Delpoit, 2010). In addition, the social worlds of substance users are expected to consist of other drug users, whose health behaviours are typically poor (Ware, Wyatt, & Tugenberg, 2006). As a result, adherence support is seldom obtained in these social circles.

2.9 Conclusion

It is believed that the most important factors influencing adherence are patient-related (WHO, 2003; Chesney, 2000). In the social sciences, and particularly the field of psychology, patient characteristics have been one of the central areas for investigation with regard to ART adherence. Despite the recent increase in research within this field, there is still a need for further investigation into the associations between patient characteristics and adherence to ART.

The above review has discussed some of the most common patient characteristics associated with adherence to ART. The literature suggested that with the possible exception of PTSD, most common mental disorders, including depression, anxiety, alcohol abuse, and substance abuse, are unequivocally negatively associated with ART adherence. Social support appeared to be positively related to ART adherence, and negatively related to common mental disorders, although these relationships seem to be specific to the demographic characteristics of the sample, and the geographical context in which the study has been conducted.

Following from the above, the present study aimed to investigate the relationships between the symptoms of depression, anxiety, PTSD, alcohol abuse, substance abuse,

perceived social support, and adherence to ART. The research design and methodology used to test these relationships are described in Chapter 3.

CHAPTER 3

Research Design and Methodology

3.1 Introduction

The following chapter describes the research design and methodology used to investigate the relationships between social support, common mental disorders and ART adherence. After some notes on the core concepts are explained, the procedures of data collection, capturing and analysis are presented, followed by a discussion of the measurement instruments. Finally, potential shortcomings and sources of error are identified.

3.2 Clarification of Concepts Used

The present study investigated the severity of symptoms of common mental disorders, and not the prevalence of common mental disorders, since no diagnostic interviews were conducted. All of the scales relating to common mental disorders are used to measure the severity of symptoms of common mental disorders. This information is not used to determine whether a patient fits the diagnostic criteria for any specific mental disorder.

Social support was measured using a self-report scale completed by the participants under investigation, rather than investigating the tangible social networks of participants. For this reason, it is in fact the level of perceived social support that is measured, and not the actual level of social support.

3.3 Ethical approval

Ethical approval for this study was granted by the Stellenbosch University Committee for Human Research. In addition, the study received ethical approval by the Western Cape Department of Health. All aspects of the study, including the participant recruitment strategy

and data collection procedures, were approved by both the Stellenbosch University Committee for Human Research and the Western Cape Department of Health.

3.4 Research Design

The present study used a quantitative survey design. The design can be described as correlational, as the study aimed to identify variables that cause change in other variables. The time-dimension of the study was cross-sectional, and as a result only correlational relationships could be investigated, while causal relationships could not be investigated.

3.5 Participant Inclusion Criteria

The population under study was patients living with HIV who had been receiving antiretroviral therapy (ART) from a state funded healthcare facility, for six months or more. At the time of the study, state funded HIV clinics usually measured their patients' CD4 counts and viral loads every six months, which meant that most patients that had been receiving ART for six months or longer had a record of CD4 count and viral load as part of their chart data. For practical and ethical reasons, participants had to be 18 years of age or older in order to qualify for the study. In summary, participants were included in the study based on the following criteria: 18 years of age or older; HIV positive; and enrolled for ART six months prior to being selected for the present study.

3.6 Participants

The sample was recruited from and consisted of HIV-infected patients receiving antiretroviral medication at Helderberg Hospital, located in the Overberg region of the Western Cape. The hospital is situated in Somerset West, 50 kilometres outside of the city of Cape Town. Patients were referred to the hospital from surrounding areas in the Overberg

district. The hospital had just over 120 inpatient beds which catered for most specialties. The HIV clinic at Helderberg Hospital had been in operation since 2004 and at the time of the study enrolled between 16 and 35 new patients per month. The clinic had two administrative assistants, two nursing sisters, one nurse's aid, two doctors, and eight patient advocates.

3.7 Sampling Strategy and Data Collection Procedures

Convenience sampling was used to recruit participants into the study. Convenience sampling is a form of non-probability sampling that involves taking in all participants qualifying for the study, until the desired sample size is obtained (Bless, Higson-Smith & Kagee, 2006).

The study was conducted at the same location where the participants were recruited, namely Helderberg Hospital's HIV clinic in Somerset West. All personnel at the clinic were briefed about the study, and nurses and administrative staff were asked to provide assistance where possible. Their assistance involved identifying patients qualifying for the study, informing patients about the study, and coordinating participation to ensure that patients do not miss clinic appointments.

The nurses at the clinic were provided with pamphlets explaining the study. As patients arrived for their appointments, the nurses informed them of the study, handed them a pamphlet, and informed them that if they wish to participate, they may approach one of the two postgraduate researchers who were waiting in a private office at the clinic. Patients who were interested in participating had the study explained to them by one of the researchers and were asked to provide informed consent if they were still willing to participate in the study. After providing informed consent, participants were requested to complete the battery of questionnaires. Participants who stated that they did not feel comfortable completing the questionnaires on their own, could ask for assistance from one of the two researchers, who

would then verbally administer the questionnaires. This was done to accommodate participants with low literacy levels. Participants were asked to speak with either one of the researchers after completing the battery of questionnaires, to allow the researcher to debrief the participant. The debriefing sessions gave the researchers an opportunity to ensure that participants did not experience any form of distress resulting from the study, and to answer any questions that the participants may have had. This process also enabled the researchers to check for missing responses on the questionnaires.

3.8 Incentives

Participants were given refreshments after they completed the questionnaires. There was no need to provide transportation as data collection was done at the same visit as patients' clinic appointments, which meant that all participants were already at the hospital to receive their antiretroviral medication.

During the course of the data collection phase, nurses and administrative staff were each provided with a R100 shopping voucher as a token of appreciation for their assistance with the study, which involved informing patients about the study, inviting them to make contact with the researchers, and assisting researchers in obtaining patient chart data. Upon completion of the data collection phase, nurses and administrative staff each received another R50 shopping voucher, again as appreciation for their assistance in the study. The financial compensation was in no way related to the amount of assistance provided by any given nurse or administrative staff member. The nurses were briefed prior to the commencement of the study, to ensure that they were familiar with the relevant ethical principles, with particular emphasis on participants' rights to autonomy and discontinuance. Stated differently, nurses were informed that patients would only be allowed to participate out of their own free will, and that were free to discontinue their involvement at any time. One of the researchers

periodically visited the recruitment area to ensure that there was no violation of or confusion with regard to the abovementioned ethical principles.

3.9 Measurement Instruments

This section provides an overview of the measurement instruments included in the battery of questionnaires, as well as other data collected at the Helderberg Hospital HIV Clinic. The battery of questionnaires consisted of a biographical questionnaire, five scales measuring symptoms of common mental disorders, a scale measuring perceived social support, and a scale measuring ART medication adherence. For an example of the battery of questionnaires, see Appendix A.

3.9.1 Biographical questionnaire.

The first part of the biographical questionnaire consisted of a section in which participants were required to write their name, surname, age, and date of birth. Following this section, there was a section with tick boxes in which participants could indicate biographical information, such as gender, by selecting the corresponding items.

3.9.2 Beck Depression Inventory – Second Edition (BDI II).

The BDI II is a 21 item self-report scale that measures severity of symptoms of depression in individuals. The BDI II classifies total scores into four categories, namely minimal depression (0-13), mild depression (14-19), moderate depression (20-28), and severe depression (29-63). In the United States, internal consistency is reported to be high, with alpha coefficients of .92 and .93 for outpatients and college students respectively. A test-retest correlation of .93 was found for 26 Philadelphia outpatients with approximately 1 week between tests. The test displayed good construct-, convergent- and discriminant validity for a

sample of Kentucky and New Jersey outpatients (Beck, Steer & Brown, 1996). The psychometric properties of a Xhosa translation of the BDI II has been tested among a sample of 122 first language Xhosa speaking people from the Eastern Cape, South Africa (Steele & Edwards, 2008). The psychometric properties were comparable to those obtained in the United States. Among the South African sample, the Xhosa translation of the BDI II demonstrated an alpha coefficient of .93. Furthermore, the item total correlations ranged from .48 to .70, in comparison to the original validation studies, which had item total correlations ranging from .39 to .70.

3.9.3 Beck Anxiety Inventory (BAI).

The BAI is a 21 item self-report scale that measures severity of symptoms of anxiety in individuals. Total scores on the BAI can be classified into four categories, namely minimal anxiety (0-7), mild anxiety (8-15), moderate anxiety (16-25), and severe anxiety (26-63). Beck and Steer (1993) has validated the scale among samples within the United States. Internal consistency was reported to be high, with alpha coefficients ranging from .92 to .94. Test-retest correlation has also been reported to be high. The test demonstrated high content, concurrent, construct, discriminant, and factorial validity for populations within the United States (Beck & Steer, 1993). The previously mentioned study by Steele and Edwards (2008) also investigated the psychometric properties of a Xhosa translation of the BAI. Again, the internal consistency ($\alpha = .92$) and item-total correlations (ranging from .44 to .71 compared to the .31 to .71 obtained in validation study) were comparable to the validation studies conducted in the United States.

3.9.4 Alcohol Use Disorders Identification Test (AUDIT).

The AUDIT is a self-report scale that screens for excessive alcohol consumption and alcohol related problems. The scale has 10 items. The total score on the AUDIT is intended to reflect the extent of alcohol involvement along a broad continuum of severity. Several studies reviewed by the authors of the scale indicate that the scale has high internal consistency as well as high test-retest reliability (Babor, Higgins-Biddle, Saunders & Monteiro, 2001). For example, among a sample of 832 clients enrolled in a drinking and driving treatment programme in the United States, the AUDIT demonstrated high internal consistency, with an alpha coefficient of .83 (Hays, Merz & Nicholas, 1995). Babor et al. (2001) reported that the AUDIT was valid for a wide variety of subpopulations, including primary care patients, emergency room cases, drug users, the unemployed, university students, elderly hospital patients, and persons of low socio-economic status. The scale has also been applied to a wide variety of countries and cultures, suggesting that it can be used as an international screening test (Babor et al., 2001). In addition to these various countries and cultures, the AUDIT has also been tested within a South African sample, among 465 individuals enrolled for ART services near Cape Town (Myer et al., 2008). Myer et al. (2008) compared results from the AUDIT with results from the Mini-International Neuropsychiatric Interview (MINI) administered within the same sample, in order to determine its sensitivity and specificity. The sensitivity and specificity of the AUDIT was reported to be good across all the subgroups of the study sample. All individuals (100%) with MINI-defined alcohol abuse or dependence were correctly classified by the AUDIT, while 79% of those who did not have MINI-defined alcohol abuse or dependence problems were correctly classified by the AUDIT.

3.9.5 Drug Use Disorders Identification Test (DUDIT).

The DUDIT is an 11 item self-report scale that screens for drug related problems, designed to be used in conjunction with the AUDIT. The DUDIT is reported to be effective in screening for drug-related problems in clinically selected groups as well as in the context of public health surveys (Berman, Bergman, Palmstierna & Schlyter, 2005). In Sweden, Berman et al. (2005) have investigated the scale's reliability and validity among heavy drug users from prison, inpatients in detoxification settings and a general population sample. The scale demonstrated good reliability, with an alpha coefficient of .80. The authors also reported that the scale had good validity, and stated that the DUDIT could predict drug dependence with a sensitivity of 90% for both DSM-4 and ICD-10 criteria.

3.9.6 PTSD Symptom Scale - Self Report (PSS-SR).

The PSS-SR is a 17 item self-report scale designed to measure the severity of PTSD symptoms in trauma victims. The psychometric properties of the scale have been assessed within the United States, in an all female sample consisting of 46 rape victims and 72 non-sexual assault victims (Foa, Riggs, Dancu & Rothbaum, 1993). With regard to internal consistency, the scale had a total score alpha coefficient of .91, and an inter-item correlation coefficient of .60. Furthermore, one month test-retest reliability was .74. In the same sample, convergent validity was investigated by evaluating the scale against the DSM-III-R PTSD Module's Structured Clinical Interview, and the PSS-SR was able to correctly identify the PTSD status of 86% of the 36 subjects used for this comparison. Based on the aforementioned finding, the authors concluded that the scale had excellent convergent validity. The PSS-SR has not yet been calibrated to provide standardised cut-off scores that can be generalised across populations. While the PSS-SR had not been validated in South Africa, the scale had been successfully used in a variety of samples (Farley, Wade &

Birchmore, 2003; Hollifield et al., 2008; Phillips, Rosen, Zoellner & Feeny, 2006), suggesting that the scale can be used for various populations. For example, in a sample of 85 Australian patients with coronary heart disease, the PSS-SR demonstrated excellent internal reliability with an alpha coefficient .88 (Farley et al., 2003). Furthermore, in Sri Lanka, the scale was used among a sample of 136 adult respondents, and the scale demonstrated excellent internal reliability with an alpha coefficient of .90 (Hollifield et al., 2008).

3.9.7 Social Support Appraisals (SSA) scale.

The SSA is a self-report scale used to measure subjective appraisals of level of social support. The scale consists of 23 items forming three subscales, measuring perceived social support from family, friends, and other individuals, respectively. Specifically, the SSA measures the extent to which the individual believes he or she is loved by, esteemed by, and involved with family, friends, and others (Corcoran & Fischer, 2000). It is based on the idea that social support is in fact support only if the individual believes it is available. The reliability and validity of the scale has been tested among 979 respondents in the United States, consisting of five community samples and five samples of college students (Vaux et al., 1986). Among these samples, the SSA demonstrated very good internal consistency, with alpha coefficients that range from .81 to .90. The SSA has been subjected to considerable evaluation of its validity, and it shows very good concurrent, predictive, known-groups, and construct validity (Vaux et al., 1986). The SSA was significantly correlated with a variety of measures of social support and psychological well-being, such as network satisfaction, perceived support, family environment, negative affect, positive affect, depression, loneliness, and life-satisfaction (Vaux et al., 1986).

3.9.8 Self-reported antiretroviral adherence.

The self-report adherence scale that was used was adapted from the self-report scale proposed by Simoni et al. (2006), which was based on a comprehensive review of both literature and clinical experience to help researchers studying HIV in constructing self-report scales for measurement of ART adherence. It was suggested that both researchers and clinicians can use the items on the proposed scale with confidence in their validity in terms of their associations of other indirect measures of adherence. Simoni et al. (2006) suggested the use of biological markers in conjunction with this scale, since reactive effects could bias the results.

3.9.9 Biological adherence data.

Biological adherence to ART was to be assessed by looking at participants' pill count, CD4 count and viral load. However, not all of these measures were included for data analysis. The pill count data was too unreliable, and in many cases completely omitted, which meant that patients' pill counts could not be tracked. CD4 count data, on the other hand, was reliable and available. Nevertheless, during data collection, it was decided that CD4 count should be excluded from analysis as it is not necessarily a direct indication of biological adherence. During data collection, the researchers consulted with Dr. Katrin Stuve, Head of the Department of Medicine and Infectious Diseases at Helderberg Hospital, who explained the limitations of CD4 count as a measure of adherence to ART. Variability of CD4 count is strongly influenced by a variety of other factors, such as the presence of opportunistic infections. For example, the presence of tuberculosis (TB) can result in a drop of CD4 count, even if the patient is adherent to ART. Viral load was the only measure of biological adherence that was excluded prior to the data analysis phase of the study.

3.10 Translation of Questionnaires

The entire battery of questionnaires was available in English, Xhosa and Afrikaans. Xhosa translations of the BDI II, BAI and SSA were obtained from Dr. Somhlaba, a lecturer from the Stellenbosch University Psychology Department. A Xhosa translation of the AUDIT was obtained from Rehana Kader, a researcher at the Medical Research Council. The DUDIT, PSS-SR and self-report adherence scale were translated by Dr. Dlali, a senior lecturer and Xhosa expert from the Stellenbosch University African Languages Department. Subsequently, these scales were sent to the Stellenbosch University Language Department, for back-translation and authentication. Feedback from the authentication process indicated that these scales were almost equal to the original English scales in terms of content and meaning.

All the Afrikaans translations were done by the principle investigator. The Afrikaans translations were back-translated by colleagues of the principle investigator, who are first language Afrikaans speakers. Again, these scales were found to be virtually equal to the original English scales in terms of content and meaning.

3.11 Data Capturing

The 107 completed questionnaires were entered into SPSS. Two integrity checks were completed on the dataset to ensure that the data was entered correctly. After the data capturing process was completed, some of the participants' data were removed from the dataset, after the researchers discovered that they did not meet the inclusion criteria. Specifically, participants 2, 4, 25, 102, and 105 were excluded as the chart data revealed that it had been less than six months since they were initiated on ART. Participant 89's data was also excluded on the basis of misunderstanding the questionnaire. The participant selected all

possible responses on several items that were clearly mutually exclusive, and provided inconsistent answers throughout the questionnaire.

3.12 Shortcomings and Sources of Error

In addition to the problems with biological adherence data discussed above, there were also some missing responses on the questionnaires. The time that each patient would be present at the clinic was limited, in some cases to as little as an hour and a half, which meant that participants had to complete their questionnaire as soon as they provided consent to participate in the study. On a small number of occasions, participants completed their questionnaires and left while both researchers were in the process of briefing new participants. Unless these patients were still present in the clinic, the researchers were unable to request that these participants complete missing responses.

3.13 Data Analysis

All analyses were conducted in SPSS, which included item response frequencies, item and total score distributions, internal reliability of measures, biserial correlations, bivariate correlations, and logistic regression analysis. The results from the analyses are discussed in Chapter 4.

In the present study, the relationships between symptoms of depression, symptoms of anxiety, symptoms of PTSD, perceived social support, and self-reported adherence to ART were investigated using biserial and bivariate correlations. Logistic regression analysis was used to further investigate the relationship between self-reported adherence to ART and the other variables mentioned above. Specifically, symptoms of depression, symptoms of anxiety, symptoms of PTSD, and perceived social support were tested as predictors, with self-reported adherence to ART being the outcome variable.

CHAPTER 4

Results

4.1 Preliminary Analysis

The results from the preliminary analysis are presented below, which includes the sample demographic characteristics, reliability analysis and item analysis.

4.1.1 Demographic characteristics of sample.

The sample included in data analysis consisted of 101 participants (83 = female, 18 = male). The participants' age in years ranged from 20 to 51 (Mean age = 35.04 years, SD = 7.05). With regard to ethnicity, 66.3% of the participants classified themselves as Black, and 31.7% as Coloured, while the remaining 2% selected the category labelled 'other'. None of the participants selected the categories labelled Indian or White. Table 1 below provides a detailed summary of the sample demographics, including gender, age, ethnicity, language, work situation, and annual family income.

Table 1

Demographic Characteristics of the Sample

	Number of respondents	% of total sample
Gender		
Male	18	17.8
Female	83	82.2
Age (years)		
20 – 29	20	29.7
30 – 39	44	43.6
40 – 49	24	23.8
50 – 51	3	3.0
Ethnicity		
Black	67	66.3
Coloured	32	31.7
Other	2	2.0
First language		
Xhosa	56	55.4
Afrikaans	32	31.7
Other	13	12.9
Current work situation		
Employed fulltime	29	28.7
Employed part-time	17	16.8
Unemployed	43	42.6
Homemaker	4	4.0
Student	4	4.0
Disabled	4	4.0
Annual family income		
Less than R10 000	40	41.7
R10 001 – R40 000	16	16.7
R40 001 – R80 000	3	3.1
R80 001 – R110 000	1	1.0
R110 001 – R170 000	0	0.0
R170 001 – R240 000	1	1.0
R240 000 and above	1	1.0
Do not know	34	35.4

Note. ^aN = 96; Five respondents did not provide a response for annual family income.

4.1.2 Reliability- and item analyses.

The BDI II ($\alpha = .88$), BAI ($\alpha = .89$), and PSS-SR ($\alpha = .92$) demonstrated excellent internal consistency. These three measures also demonstrated sufficient variation, allowing distinction between different levels of symptom severity.

Both the AUDIT ($\alpha = .85$) and DUDIT ($\alpha = .80$) demonstrated excellent internal consistency. However, for both these measures, the item and total score distributions were severely skewed towards the bottom end of the respective scales. These measures failed to distinguish between different levels of alcohol and drug use, respectively. Removing items from the scales was not an option, since all the items on each respective scale are required to provide a measure of alcohol or substance abuse. In isolation, each individual item on the AUDIT does not reflect alcohol abuse, and each individual item on the DUDIT does not reflect drug abuse. In other words, if only certain items are retained, the respective scales may no longer be measuring alcohol and substance abuse. For these reasons, the AUDIT and DUDIT were not included in the main analysis.

The original SSA ($\alpha = .89$) demonstrated excellent overall internal consistency. The family support subscale ($\alpha = .77$) and the friends support subscale ($\alpha = .78$) demonstrated good internal consistency. The other support subscale ($\alpha = .68$) demonstrated modest internal consistency.

Exploratory factor analysis revealed that the reverse scored items loaded onto different factors than the forward scored items. A review of the literature on the scale revealed no evidence that the scale had been standardised within South Africa samples. To ensure that each subscale measured a unidimensional factor, all the items that did not load onto the first factor of each subscale (i.e. the reverse scored items) were dropped from the respective subscales and excluded from all further analysis.

After item exclusion, the SSA demonstrated excellent internal consistency ($\alpha = .93$). The family support subscale ($\alpha = .83$), friends support subscale ($\alpha = .86$), and other support subscale ($\alpha = .82$) all demonstrated excellent internal consistency.

The majority of the sample participants' viral loads were suppressed. Out of the total 93 participants' viral loads that could be obtained, 71 (76.3%) of the participants had viral loads that were lower than the detectable limit (LDL). Despite the availability of the viral load data, it was decided that viral load would not be suitable for the analysis used in the present study. While any given patient's viral load can take on a number of values, the exact values do not necessarily reflect a specific level of adherence. Essentially, there are only two values, namely LDL, which means that the viral load is suppressed, or within detectable limit, which means that the viral load is not suppressed. The viral load data could be used to create a dichotomous variable which provides a distinction between adherent and non-adherent patients. However, the problem is that it is difficult to define exactly what 'adherent' and 'non-adherent' means when making this distinction. It should be noted that a patient with a LDL viral load could also be non-adherent. The Helderberg Hospital HIV Clinic staff explained that it would not be possible to determine the exact amount of time it would take before a given non-adherent patient's viral load is no longer suppressed. This amount of time cannot be accurately estimated as it is influenced by various factors, such as CD4 count, time since infection, previous history of opportunistic infections, stage of diagnoses, and nutritional status. For these reasons, it is problematic to classify participants' adherence based on their viral loads.

The Self- Reported Antiretroviral Adherence scale was used to create a binary variable distinguishing between perfect adherence (coded as 0) and non-perfect adherence (coded as 1). Participants were classified as having non-perfect adherence if they indicated anything less than perfect adherence to their medication schedule. The criteria for classifying

a participant as having non-perfect self-reported adherence are as follows: 1) Forgetting to take medication over the previous weekend; 2) Missing one or more doses in the previous seven days; 3) Forgetting to take medication during the previous two weeks; 4) Indicating less than 100% adherence to medication during the previous month; 5) Discontinuing taking of medication when feeling better; 6) Discontinuing taking of medication when feeling worse. This binary measure demonstrated good variation, with 54.5% of participants being classified as having perfect adherence, while 45.5% were classified as having non-perfect adherence.

The internal consistency (Cronbach's alpha), mean and standard deviation (SD) for each of the continuous measures are summarised in Table 2.

Table 2

Cronbach's Alpha, Mean and Standard Deviation (SD) for Each Continuous Measure

	N	α	Mean	SD
BDI II	94	.88	16.6	11.3
BAI	87	.89	11.6	11.2
AUDIT	90	.85	3.7	5.9
DUDIT	98	.80	1.0	3.1
PSS-SR	86	.92	10.8	10.7
SSA ^a	89	.93	59.1	10.2
SSA – Family support subscale	98	.83	20.0	3.7
SSA – Friends support subscale	98	.86	19.3	4.0
SSA – Other support subscale	94	.82	19.5	3.5

Note. ^aThe SSA statistics in this table were calculated after item exclusion.

4.1.3 Severity of symptoms of common mental disorders.

The cut-off scores on the BDI II and BAI were used to determine the severity of symptoms of common disorders within the study sample. Since the PSS-SR did not have standardised total scores that can be generalised across populations, it was not included in this section. Participant total scores on the BDI II and BAI were classified into the different

categories of severity outlined in Chapter 3. Results from the classifications for severity of symptoms of depression and anxiety are presented in Table 3 below.

Table 3

Classifications for Severity of Symptoms of Depression and Anxiety

	Cut-off scores	Number of respondents	% of respondents ^a
BDI II		94	100
Minimal depression	0-13	45	47.9
Mild depression	14-19	11	11.7
Moderate depression	20-28	21	22.3
Severe depression	29-63	17	18.1
Excluded (missing data)		7	
BAI		87	100
Minimal anxiety	0-7	37	42.5
Mild anxiety	8-15	25	28.7
Moderate anxiety	16-25	18	20.7
Severe anxiety	26-63	7	8.0
Excluded (missing data)		14	

Note. ^aThis is the percentage of valid respondents included in the frequency distribution. That is, respondents with no missing data for the respective scale.

4.1.4 Bivariate and biserial correlations.

Kendall's tau was used to calculate bivariate correlations between all the total scores that were selected for the main analysis, namely that of the BDI II, the BAI, the PSS-SR, the SSA and its three subscales. In this case, Pearson's correlation coefficient could not be used, as the distribution curves of scores on all the measures were non-normal. Both Spearman's correlation coefficient and Kendall's tau are appropriate when dealing with non-normally distributed data (Field, 2005). In this case, Kendall's tau was selected because of the relatively small size of the data set. In addition, it has been suggested that compared to Spearman's correlation coefficient, Kendall's tau provides more accurate generalisations to the population (Field, 2005). Correlations between the dichotomous measure of adherence

and the other variables were calculated using biserial correlation coefficients. Missing data were excluded pairwise. The results of these correlations are presented in Table 4 below.

Table 4

Kendall's Tau Correlations for Each Measure and Biserial Correlations for Adherence

		Adherence	BDI II	BAI	PSS-SR	SSA	SSA-Family	SSA-Friends	SSA-Other
Adherence	Correlation coefficient	1							
	Sig. (2-tailed)								
	N	101							
BDI II	Correlation coefficient	-.289**	1						
	Sig. (2-tailed)	.008							
	N	94	94						
BAI	Correlation coefficient	-.193	.422***	1					
	Sig. (2-tailed)	.087	.000						
	N	87	83	87					
PSS-SR	Correlation coefficient	-.147	.438***	.430***	1				
	Sig. (2-tailed)	.197	.000	.000					
	N	86	82	77	86				
SSA	Correlation coefficient	.155	-.292***	-.266**	-.220**	1			
	Sig. (2-tailed)	.167	.000	.001	.006				
	N	89	83	79	79	89			
SSA-Family	Correlation coefficient	.098	-.322***	-.244**	-.233**	.741***	1		
	Sig. (2-tailed)	.373	.000	.002	.003	.000			
	N	98	92	86	84	89	98		
SSA-Friends	Correlation coefficient	.103	-.272***	-.226**	-.234**	.782***	.554***	1	
	Sig. (2-tailed)	.347	.000	.004	.003	.00*	.000		
	N	98	91	84	85	89	95	98	
SSA-Other	Correlation coefficient	.137	-.225**	-.188*	-.122	.776***	.545***	.619***	1
	Sig. (2-tailed)	.222	.003	.018	.130	.000	.000	.000	
	N	94	88	83	82	89	92	91	94

Note. Adherence is coded as 0 = non-perfect adherence; 1 = perfect adherence. * $p < .05$ ** $p < .01$ *** $p < .001$.

4.2 Logistic Regression Analysis

Logistic regression analysis was used to determine the extent to which change in adherence can be predicted by symptoms of depression (BDI II), anxiety (BAI), PTSD (PSS-SR), and level of perceived social support (SSA). The hierarchical method of entry was used, so that the order in which the variables were entered could be selected purely based on the reviewed literature and results from previous research. The predictor variables were entered in the following sequence: 1) BDI II; 2) BAI; 3) PSS-SR; 4) SSA. These four variables were entered in four separate blocks, starting with the first block containing only the first predictor, and finishing with the final block containing all four predictors. Note that the BAI, PSS-SR, and SSA were included in the logistic regression analysis even though it was not significantly correlated with adherence. This decision was made in light of the reviewed literature, suggesting that anxiety, PTSD and perceived social support should, theoretically, be related to medication adherence. The outcome variable was self-reported adherence, as discussed in section 4.1.2.

Two key changes were made to the dataset to prepare it for logistic regression analysis. The first was to recode the continuous predictor variables (BDI II, BAI, PSS-SR, and SSA) into categorical variables. This was done to allow a simpler and more meaningful interpretation of the analysis. The predictor variables were each given two levels, thereby creating four binary predictor variables. The predetermined classification scores of the BDI II and BAI (Beck & Steer, 1993; Beck et al., 1996) were used to recode these variables. With the BDI II, scores below 20 were coded as ‘minimal to mild depression’, while scores equal to and above 20 were coded as ‘moderate to severe depression’. Similarly for the BAI, scores below 16 were coded as ‘minimal to mild anxiety’, while scores equal to and above 16 were coded as ‘moderate to severe anxiety’. No standardised classification scores could be obtained for the PSS-SR and SSA. As an alternative, the median value for each scale was

used to recode the variables, to ensure that there would be sufficient variation on these variables. Scores on the PSS-SR falling below the median value of 10 were classified as ‘low amount of symptoms of PTSD’, while those equal to and above 10 were classified as ‘high amount of symptoms of PTSD’. Likewise, scores on the SSA falling below the median value of 41 were classified as ‘low level of social support’, while those equal to and above 41 were classified as ‘high level of social support’. The labels given to the different levels on the PSS-SR and SSA are completely arbitrary, and do not reflect any actual level of symptoms or perceived social support.

The second key change made to the dataset was the imputation of data. If the dataset was used for the analysis without imputing data, 32 participants would be excluded from the analysis. This would result in an effective sample size of only 69, meaning that only 68.3% of the actual sample participants would be included in the analysis. This could create unnecessary bias, which would ultimately call the validity of the results into question. In addition, the smaller sample size would result in less statistical power, making it more difficult to detect effects that exist in the population. In nearly all cases, there was no more than 1 missing response on a given scale of a given participant. There was only one case where a participant had 3 missing responses on a single scale. The data were imputed by substituting missing values with the mean value of the remaining items on the scale, for each respective participant and scale. For example, if a participant had a missing response on the BDI II, the average value of that participant’s remaining responses on the BDI II was used to replace the missing response. As a result of imputed data, the analysis was done on an effective sample size of 101.

Table 5 illustrates how the predictor variables and outcome variable were coded. This is followed by the summary of each model presented in Table 6, while Table 7 provides an overview of the predictors in each model. Finally, Table 8 provides a classification summary

for each respective model, demonstrating how accurate each model was in predicting whether participants would be classified as having either perfect- or non-perfect adherence.

Table 5

Coding of Variables for Binary Logistic Regression Analysis

Variable	Label	Frequency	Parameter coding
Adherence	Non-perfect adherence	46	0
	Perfect adherence	55	1
BDI II	Minimal to mild depression	59	1
	Moderate to severe depression	42	0
BAI	Minimal to mild anxiety	69	1
	Moderate to severe anxiety	32	0
PSS-SR	Low symptoms of PTSD	50	1
	High symptoms of PTSD	51	0
SSA	Low social support	47	1
	High social support	54	0

Note. Coding was done in such a way that it would not be necessary to invert odds ratios during interpretation of results.

Table 6

Logistic Regression Analysis: Summary of Models

Model	Chi-square (Block)	p (Block)	Chi-square (Model)	p (Model)	-2 Log Likelihood	Cox & Snell R ²	Nagelkerke R ²
1 ^a	7.830	.005**	7.830	.005**	131.383	.075	.100
2 ^b	0.509	.457	8.339	.015*	130.873	.079	.106
3 ^c	2.436	.119	10.776	.013*	128.437	.101	.135
4 ^d	0.246	.620	11.021	.026*	128.191	.103	.108

Note. ^aPredictor: BDI II. ^bPredictors: BDI II; BAI. ^cPredictors: BDI II; BAI; PSS-SR.

^dPredictors: BDI II; BAI; PSS-SR; SSA. * $p < .05$ ** $p < .01$.

Table 7

Logistic Regression Analysis: Summary of Predictors in Each Model

Model	Predictor	B (SE)	Wald χ^2	p	Odds Ratio	CI
1	BDI II	1.153 (0.420)	7.532	.006**	3.169	1.391 – 7.221
2	BDI II	1.005 (0.467)	4.635	.031*	2.731	1.094 – 6.815
	BAI	0.354 (0.495)	0.513	.474	1.425	0.540 – 3.760
3	BDI II	0.830 (0.484)	2.943	.086	2.292	0.888 – 5.914
	BAI	0.034 (0.542)	0.004	.950	1.035	0.358 – 2.993
	PSS-SR	0.769 (0.493)	2.432	.119	2.157	0.821 – 5.668
4	BDI II	0.827 (0.484)	2.922	.087	2.287	0.886 – 5.905
	BAI	0.042 (0.542)	0.006	.938	1.043	0.360 – 3.019
	PSS-SR	0.724 (0.500)	2.095	.148	2.063	0.774 – 5.502
	SSA	-0.214 (0.431)	0.246	.620	0.808	0.347 – 1.878

Note. * $p < .05$ ** $p < .01$.

Table 8

Logistic Regression Analysis: Classification Summary for Each Model

	Observed	Predicted		Percentage correct ^a
		Non-perfect adherence	Perfect adherence	
Intercept				54.5
	Non-perfect adherence	0	46	0
	Perfect adherence	0	55	100
Model 1				64.4
	Non-perfect adherence	26	20	56.5
	Perfect adherence	16	39	80.9
Model 2				64.4
	Non-perfect adherence	26	20	56.5
	Perfect adherence	16	39	80.9
Model 3				66.3
	Non-perfect adherence	22	24	47.8
	Perfect adherence	10	45	81.8
Model 4				68.3
	Non-perfect adherence	25	21	54.3
	Perfect adherence	11	44	80

Note. ^aFor each model, the overall percentage of correct classification is given, followed by the percentages of correct classification for each of the two categories.

4.2.1 Assessment of models

Model 1 was significantly ($p < .01$) better at predicting whether a participant was in the perfect or non-perfect adherence category than using only the intercept as a model. With the BDI II as predictor, the model could correctly predict to which category 64.4% of participants would belong to, as opposed to 54.5% when using the intercept as a model. Model 1 predicted that patients reporting perfect adherence to their medication, were around three times ($OR = 3.169$, $CI = 1.391 - 7.221$) less likely to report moderate to severe symptoms of depression.

In Model 2, both the BDI II and BAI were used as predictors of adherence. Model 2 was not significantly ($p = .475$) better at predicting adherence than Model 1. However, Model 2 was significantly ($p < .05$) better at predicting adherence than using the intercept as a model. Model 1 and Model 2 were equivalent in terms of the sensitivity and specificity of their predictions, and both models correctly classified 66.7% of participants. As was the case with Model 1, using the BDI II variable in Model 2 also predicted that patients reporting perfect adherence to their medication were approximately 3 times ($OR = 2.731$, $CI = 1.094 - 6.815$) less likely to report moderate to severe symptoms of depression.

Model 3 was not significantly ($p = .119$) better at predicting adherence than Model 2, but it was significantly ($p < .05$) better at predicting adherence than using the intercept as a model. The percentage of correct classifications for Model 3 was slightly higher than for Model 1 and 2, increasing from 64.4% to 66.3%.

Model 4 included all four predictor variables, namely the BDI II, BAI, PSS-SR, and SSA. Model 4's percentage of correct classifications was 68.3%, which is 3.9% more than that of Model 1 and 2, and 2% higher than that of Model 3. Model 4 was not significantly ($p = .620$) better at predicting adherence than Model 3. As with the previous models, it was significantly ($p < .05$) better at predicting adherence than using the intercept as a model.

4.2.2 The BDI II as predictor of adherence

In the present study, all four models were significantly better at predicting adherence than using the intercept as a model. However, the results suggested that the BDI II (symptoms of depression) was the only significant predictor. In all the models subsequent to Model 1, the inclusion of the BAI, PSS-SR, and SSA did not make any significant contribution to predicting whether participants would have perfect or non-perfect adherence. This finding is in keeping with the fact that the BDI II was the only predictor that had a significant biserial correlation with adherence.

4.2.3 Multicollinearity

According to Field (2005), it is essential to test for multicollinearity following a logistic regression analysis, as collinearity among variables can have a biasing effect. When assessing for collinearity between variables, Field (2005) suggests that tolerance values of less than .1 are indicative of serious collinearity problems. In addition, it is suggested that a variance inflation factor (VIF) of greater than 10 could indicate collinearity problems and should be investigated further (Field, 2005). The VIF and tolerance statistics of all variables in the present analysis were well within these limits. Therefore, it was concluded that multicollinearity was not a problem in the present analysis.

CHAPTER 5

Discussion and Recommendations

5.1 Introduction

The present study was designed to investigate the relationship between symptoms of common mental disorders and adherence to ART. This chapter provides a discussion of the relevant findings, study limitations, and makes recommendations for future research.

5.2 Interpretation of Findings

5.2.1 Symptoms of common mental disorders.

Results from the BDI II and BAI, indicated that 40.4% of the sample reported moderate to severe symptoms of depression, while 28.7% of the sample reported moderate to severe symptoms of anxiety. These results supported findings from previous studies suggesting that common mental disorders, or in this case symptoms of depression and anxiety, may be prevalent among people living with HIV (Brandt, 2009; Freeman et al., 2008; Kagee & Martin, 2010). The study by Kagee and Martin (2010) investigated the severity of symptoms of depression among a sample of patients living with HIV, at the same clinic used for the present study, namely Helderberg Hospital HIV Clinic. Based on scores from the first edition of the Beck Depression Inventory (BDI), the authors found that 37.6% of participants fell within the moderate to severe ranges of depression, only 2.8% less than that of the current study.

As discussed in the analysis chapter, the PSS-SR did not have standardised scores that could be used to assess the severity of symptoms in the present study sample. Likewise, due to the questionable responses on the AUDIT and DUDIT, the presence and severity of alcohol- and drug abuse in the present sample are not discussed here. Limitations surrounding the use of the AUDIT and DUDIT in the present study sample are discussed in section 5.3.

5.2.2 Perceived social support and common mental disorders.

The Kendall's Tau correlations illustrated an inverse correlation between the SSA and the measures of common mental disorders, namely the BDI II, BAI and PSS-SR. In addition, with the exception of the non-significant relationship between the PSS-SR and the 'other support' subscale from the SSA, there were significant inverse correlations between all the subscales measuring level of perceived social support and the three scales measuring severity of symptoms of common mental disorders. In the present sample then, perceived social support from family, friends and others are all negatively associated with severity of symptoms of common mental disorders. These findings are in keeping with the theory that perceived social support may act as a buffer for symptoms of psychological distress (Cohen & Thomas, 1985), or specifically symptoms of depression, anxiety and PTSD.

5.2.3 Common mental disorders and self-reported adherence.

Based on the biserial correlations, the only scale that was significantly ($p < .01$) correlated with adherence was the BDI II, measuring symptoms of depression. Likewise, results from the first two models in the logistic regression analysis, suggested that symptoms of depression is the only variable that can significantly predict whether participants would belong to the perfect adherence or non-perfect adherence category. In the final two models tested in logistic regression analysis, which took into account the variance of all the predictor variables, the effect of the BDI II was no longer significant.

Therefore, results from the biserial correlations and logistic regression analysis suggested that severity of symptoms of depression was, at least to some extent, negatively associated with adherence to ART. This finding is in keeping with literature suggesting that depression can act as a barrier to ART adherence (e.g. Gordillo et al., 1999; Ammasari et al.,

2004; Campos et al., 2008). This finding is of particular importance considering the prevalence of moderate and severe symptoms of depression within the current sample, and the overall prevalence of depression among patients living with HIV in South Africa (Freeman et al., 2008).

5.2.4 Associations between different forms of social support.

The bivariate correlations between the three subscales of the SSA, namely family support, friends support and other support, were all significant. This was to be expected, since the different subscales formed part of the same underlying variable, namely the overall level of perceived social support.

5.2.5 Associations between depression, anxiety and PTSD.

There were also significant bivariate correlations between total scores of the BDI II, BAI and PSS-SR. Theoretically, depression, anxiety and PTSD should be strongly associated with one another, as they have been reported to be co-morbid, and as some of the symptoms of these disorders overlap (American Psychiatric Association [DSM-IV-TR], 2000).

5.3 Limitations

5.3.1 Small sample size.

The final sample included for data analysis consisted of 101 participants. As a general rule of thumb, a sample size of 15 participants per predictor is recommended for regression analysis (Field, 2005). Therefore, the effective sample size of 101 was sufficient for the present analysis given the approximate cut-off of 60 or greater that was required. However, smaller samples result in a lower statistical power, which makes it difficult to detect effects that could exist in the population (Field, 2005). A larger sample size also increases the

chances that the sample would reflect an accurate representation of the population under investigation (Field, 2005).

5.3.2 Representation of population within sample.

It was difficult to determine whether the sample was representative of the population of people receiving ART at state funded HIV clinics, as convenience sampling was used to recruit the participants, and recruitment was done at only one clinic. However, it was encouraging that results obtained from the present study sample were similar to that of the sample taken from the same population by Kagee and Martin (2010).

5.3.3 Cross-sectional non-experimental design.

As the present study was cross-sectional and did not use an experimental design, it was not possible to make claims regarding the direction of causality of the predicted relationships. Stated differently, while there were significant associations between variables, it was not possible to identify any given variable as causing the change observed in one or more of the other variables.

5.3.4 Measuring self-reported adherence.

One of the items used to measure self-reported adherence, was a visual analog scale (see Appendix A, question number 120). During data analysis, it became clear that the use of a visual analog scale might not be appropriate for investigating the population under investigation.

Even though this scale was explained to the participants, most participants still indicated that they did not understand how to indicate their level of ART adherence on this scale. Although the validity of this scale was not the subject of investigation for the present

study, it is acknowledged that this scale may not be a valid measure of self-reported adherence in South African patients receiving ART in a public healthcare setting.

Most of the other items measuring self-reported adherence had skewed distributions, and failed to distinguish between different levels of adherence. Also, while all these items reflect some form of self-reported adherence, they are measured on different scales, which make it difficult to construct a composite measure for data analysis. In addition, the amount of possible responses was limited to two or three on some questions, essentially allowing less variation. A possible alternative would be to construct a number of items reflecting self-reported adherence that are measured on a 5-point Likert scale. This would encourage greater variability, and allow the construction of a composite measure that can be used to create both categorical and continuous variables.

5.3.5 Self-reported alcohol and substance abuse.

The data obtained from the self-reported measures of alcohol and substance abuse were completely skewed towards the bottom end of the scale, and failed to distinguish between different levels of alcohol and substance abuse. It is possible that there were very few participants in this sample with alcohol and substance abuse problems. On the other hand, it is also possible that this self-reported measure did not provide an accurate reflection of the actual level of alcohol use. Alcohol use and recreational drug use was strongly discouraged by the clinic staff, and it is possible that participants may have underreported their alcohol use out of fear that the clinic staff would find out.

5.3.6 Literacy of participants.

The participants involved in the present study were not screened to determine their level of literacy. It is possible that some participants did not fully understand some of the

questions and instructions on the questionnaires. However, participants were instructed to ask the researchers for assistance if they were not clear on any of the instructions, or if they did not fully understand any of the questions. The researchers also reviewed the completed questionnaires to ensure that each participant's completed questionnaire was filled out according to the instructions given by the researchers and stipulated on the questionnaires. Even so, low literacy levels are acknowledged as a potential source of error.

5.4 Recommendations

Previous studies have suggested an inverse relationship between symptoms of depression and ART adherence (e.g. Gordillo et al., 1999; Ammasari et al., 2004; Campos et al., 2008), and these findings appear to be supported by the present study. More research on larger and more representative samples is necessary to determine whether this relationship is robust and can be replicated in South African samples. For a more representative sample, a randomised multi-stage sampling technique is recommended, so as to allow generalisation of findings to the population of patients receiving ART from public health clinics. Future studies could also use an experimental, longitudinal research design in order to investigate the causality of this relationship. Furthermore, the development of a comprehensive measure of self-reported adherence, that may better identify patients that are not adherent to their medication, would be a timely addition to the literature.

No significant relationships were found between anxiety, PTSD and self-reported adherence. In order to determine whether these relationships exist within the population of ART users, and other similar populations, it is recommended that these relationships are investigated using a larger sample. Again, future studies could also use an experimental, longitudinal research design in order to investigate the causality of these relationships.

The results of the present study suggest negative associations between perceived social support and the severity of symptoms of mental disorders. In light of the literature suggesting that social support can act as a protective factor with regard to life stress and mental health problems (e.g. Cohen & Thomas, 1985; Cruza-Guet et al., 2008; Dalgard et al., 2006; Dobkin et al., 2002; Kawachi and Berkman 2001; Maulik et al., 2010; Serovich et al., 2001; Takizawa et al., 2006; Wildes et al., 2002), future studies and interventions aimed at addressing common mental disorders among people living with HIV, should consider the value of social support in this regard. It has been suggested that social support provided by family may be an underutilised resource in ART adherence (Davies et al., 2006). That being said, it must be kept in mind that providing social support for people living with HIV can be a particularly problematic issue, as they are often the victims of stigmatisation and discrimination (Rao et al., 2007; Rintamaki et al., 2006).

The present study could not determine whether the near absence of alcohol and substance abuse within the study sample was an accurate reflection of alcohol and substance abuse within the study population. Future studies could investigate the association between self-reported and biological measures of alcohol and substance abuse among patients receiving ART at state funded HIV facilities. This would allow validation of self-reported measures of alcohol and substance abuse among this population.

5.5 Concluding Remarks

The available literature suggests that depression acts as a barrier to adherence among people living with HIV. With the limitations and shortcomings of the present study kept in mind, there is some preliminary evidence, however little, to support the notion that depression may be a barrier to adherence among patients receiving ART in South Africa. Further investigation is required to establish if and to what extent this is a problem. In the

absence of more research, it is risky to start making recommendations regarding policy decisions and interventions aimed at addressing depression among people living with HIV with the specific goal of improving adherence to medication. However, that is not to say that managing depression among people living with HIV should not be a public health concern, since with or without potential adverse implications for antiretroviral medication adherence, depression does have inherent negative implications for quality of life.

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11. WHICH OF THE FOLLOWING BEST DESCRIBES YOUR APPROXIMATE ANNUAL FAMILY INCOME FROM ALL SOURCES, BEFORE TAXES?

- | | |
|---|--|
| <input type="checkbox"/> Less than R10 000 | <input type="checkbox"/> R10 001-R40 000 |
| <input type="checkbox"/> R40 001-R80 000 | <input type="checkbox"/> R80 001-R110 000 |
| <input type="checkbox"/> R110 001-R170 000 | <input type="checkbox"/> R170 001-R240 000 |
| <input type="checkbox"/> R240 001 and above | <input type="checkbox"/> Don't know |

12. WHERE WERE YOU BORN?

- ☐ Town ☐ City ☐ Farm

13. WHAT IS YOUR FIRST LANGUAGE? _____

14. WHICH OTHER LANGUAGES DO YOU SPEAK? _____

INSTRUCTIONS: This section consists of 21 groups of statements. Please read each group of statements carefully, and then pick out ONE STATEMENT in each group that best describes the way you have been feeling during the PAST TWO WEEKS, INCLUDING TODAY. Make an (X) in the box next to the statement you have picked.

<p>15.</p> <p><input type="checkbox"/> I do not feel sad</p> <p><input type="checkbox"/> I feel sad much of the time</p> <p><input type="checkbox"/> I feel sad all of the time</p> <p><input type="checkbox"/> I am so sad or unhappy that I can't stand it</p>
<p>16.</p> <p><input type="checkbox"/> I am not discouraged about my future</p> <p><input type="checkbox"/> I feel more discouraged about my future than I used to be</p> <p><input type="checkbox"/> I do not expect things to work out for me</p> <p><input type="checkbox"/> I feel my future is hopeless and will only get worse</p>
<p>17.</p> <p><input type="checkbox"/> I do not feel like a failure</p> <p><input type="checkbox"/> I have failed more than I should have</p> <p><input type="checkbox"/> As I look back, I see a lot of failures</p> <p><input type="checkbox"/> I feel I am a total failure as a person</p>
<p>18.</p> <p><input type="checkbox"/> I get as much pleasure as I ever did from the things I enjoy</p> <p><input type="checkbox"/> I don't enjoy things as much as I used to</p> <p><input type="checkbox"/> I get very little pleasure from the things I used to enjoy</p> <p><input type="checkbox"/> I can't get pleasure from the things that I used to enjoy</p>
<p>19.</p> <p><input type="checkbox"/> I don't feel particularly guilty</p> <p><input type="checkbox"/> I feel guilty over many things I have done or should have done</p> <p><input type="checkbox"/> I feel guilty most of the time</p> <p><input type="checkbox"/> I feel guilty all the time</p>

20.

- ☐ I don't feel I am being punished
- ☐ I feel I may be punished
- ☐ I expect to be punished
- ☐ I feel I am being punished

21.

- ☐ I feel the same about myself as ever
- ☐ I have lost confidence in myself
- ☐ I am disappointed in myself
- ☐ I dislike myself

22.

- ☐ I don't criticize or blame myself more than usual
- ☐ I am more critical of myself than I used to be
- ☐ I criticize myself for all my faults
- ☐ I blame myself for everything bad that happens

23.

- ☐ I don't have any thoughts of killing myself
- ☐ I have thoughts of killing myself, but I would not carry them out
- ☐ I would like to kill myself
- ☐ I would kill myself if I had the chance

24.

- ☐ I don't cry any more than I used to
- ☐ I cry more than I used to
- ☐ I cry over every little thing
- ☐ I feel like crying, but I can't

25.

- ☐ I am no more restless or wound up than usual
- ☐ I feel more restless or wound up than usual
- ☐ I am so restless or agitated that it's hard to stay still
- ☐ I am so restless or agitated that I have to keep moving or doing something

26.

- ☐ I have not interest in other people or activities
- ☐ I am less interested in other people or things than before
- ☐ I have lost most of my interest in other people or things
- ☐ It's hard to get interested in anything

27.

- ☐ I make decisions about as well as ever
- ☐ I find it more difficult to make decisions than usual
- ☐ I have much greater difficulty in making decisions than I use to
- ☐ I have trouble making any decisions

28.

- ☐ I do not feel I am worthless
- ☐ I don't consider myself as worthwhile and useful as I used to
- ☐ I feel more worthless as compared to other people
- ☐ I feel utterly worthless

29.

- ☐ I have as much energy as ever
- ☐ I have less energy than I used to have
- ☐ I don't have energy to do very much
- ☐ I don't have enough energy to do anything

30.

- ☐ I have not experienced any change in my sleeping pattern
- ☐ I sleep somewhat more than usual
- ☐ I sleep somewhat less than usual
- ☐ I sleep a lot more than usual
- ☐ I sleep a lot less than usual
- ☐ I sleep most of the day
- ☐ I wake up 1-2 hours early and can't get back to sleep

31.

- ☐ I am no more irritable than usual
- ☐ I am more irritable than usual
- ☐ I am much more irritable than usual
- ☐ I am irritable all the time

32.

- ☐ I have not experienced any change in my appetite
- ☐ My appetite is somewhat less than usual
- ☐ My appetite is somewhat greater than usual
- ☐ My appetite is much less than before
- ☐ My appetite is much greater than usual
- ☐ I have no appetite at all
- ☐ I crave food all the time

33.

- ☐ I can concentrate as well as ever
- ☐ I can't concentrate as well as usual
- ☐ It's very hard to keep my mind on anything for very long
- ☐ I find I can't concentrate on anything

34.

- ☐ I am no more tired or fatigued than usual
- ☐ I get more tired or fatigued more easily than usual
- ☐ I am too tired or fatigued to do a lot of the things I used to do
- ☐ I am too tired or fatigued to do most of the things I used to do

35.

- ☐ I have not noticed any recent change in my interest in sex
- ☐ I am less interested in sex than I used to be
- ☐ I am much less interested in sex now
- ☐ I have lost interest in sex completely

Below is a list of the common symptoms of anxiety. Indicate how much you have been bothered by each symptom during the PAST WEEK, INCLUDING TODAY, by placing an X in the corresponding space in the column next to each symptom.

	NOT AT ALL	MILDLY It did not bother me much	MODERATELY It was very unpleasant but I could stand it	SEVERELY I could barely stand it
36. Numbness or tingling	0	1	2	3
37. Feeling hot	0	1	2	3
38. Wobbliness in legs	0	1	2	3
39. Unable to relax	0	1	2	3
40. Fear of the worst happening	0	1	2	3
41. Dizzy or lightheaded	0	1	2	3
42. Heart pounding or racing	0	1	2	3
43. Unsteady	0	1	2	3
44. Terrified	0	1	2	3
45. Nervous	0	1	2	3
46. Feelings of choking	0	1	2	3
47. Hands trembling	0	1	2	3
48. Shaky	0	1	2	3
49. Fear of losing control	0	1	2	3
50. Difficulty breathing	0	1	2	3
51. Fear of dying	0	1	2	3
52. Scared	0	1	2	3
53. Indigestion or discomfort in abdomen	0	1	2	3
54. Faint	0	1	2	3
55. Face flushed	0	1	2	3
56. Sweating (Not due to heat)	0	1	2	3

The following questions ask about your use of alcohol. Please answer them as correctly and honestly as possible by making an (X) in the box that is most true for you.

57. How often do you have a drink containing alcohol?	Never	Monthly or less	2-4 times a month	2-3 times a week	4 or more times a week
58. How many drinks containing alcohol do you have on a typical day when you are drinking?	1 or 2	3 or 4	5 or 6	7 to 9	10 or more
59. How often do you have six or more drinks on one occasion?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily
60. How often during the last year have you found that you were not able to stop drinking once you had started?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily
61. How often during the last year have you failed to do what was normally expected of you because of drinking?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily
62. How often during the last year have you needed a first drink in the morning to get yourself going after a heavy drinking session?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily
63. How often during the last year have you had a feeling of guilt or remorse after drinking?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily
64. How often during the last year have you been unable to remember what happened the night before you were drinking?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily
65. Have you or someone else been injured because of your drinking?	No		Yes, but not in the last year		Yes, during the last year
66. Has a relative, friend, doctor, or other health care worker been concerned about your drinking or suggested you cut down on your own?	No		Yes, but not in the last year		Yes, during the last year

The following questions ask about your use of drugs. Please answer them as correctly and honestly as possible by making an (X) in the box that is most true for you.

67. How often do you use drugs other than alcohol?	Never	Once a month or less often	2-4 times a month	2-3 times a week	4 times a week or more often
68. Do you use more than one type of drug on the same occasion?	Never	Once a month or less often	2-4 times a month	2-3 times a week	4 times a week or more often
69. How many times do you use drugs on a typical day when you use drugs?	0	1-2	3-4	5-6	7 or more
70. How often are you influenced heavily by drugs?	Never	Less often than once a month	Every month	Every week	Daily or almost every day
71. Over the past year, have you felt that you longing for drugs was so strong that you could not resist it?	Never	Less often than once a month	Every month	Every week	Daily or almost every day
72. Has it happened, over the past year, that you have not been able to stop taking drugs once you started?	Never	Less often than once a month	Every month	Every week	Daily or almost every day
73. How often over the past year have you taken drugs and neglected to do something you should have done?	Never	Less often than once a month	Every month	Every week	Daily or almost every day
74. How often over the past year have you needed to take a drug the morning after heavy drug use the day before?	Never	Less often than once a month	Every month	Every week	Daily or almost every day
75. How often over the past year have you had guilt feelings or a bad conscience because you had drugs?	Never	Less often than once a month	Every month	Every week	Daily or almost every day
76. Have you or anyone else been hurt (mentally or physically) because you used drugs?	No		Yes, but not over the past year		Yes, over the past year

77. Has a relative or a friend, a doctor or a nurse, or anyone else, been worried about your drug use or said to you that you should stop using drugs?	No	Yes, but not over the past year	Yes, over the past year
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Directions: Below is a list of the problems that people sometimes have after experiencing a traumatic event. Read each one carefully and use an (X) in the box with the number that best describes how often that problem has bothered you in the PAST 2 WEEKS. Rate each problem with respect to the traumatic event that brought you into treatment.

	Not at all/ only one time	Once per week or less/ once in a while	2 to 4 times per week/ half the time	5 or more times per week/ almost always
78. Having upsetting thoughts or images about the traumatic event that came into your head even though you didn't want them to?	0	1	2	3
79. Having bad dreams or nightmares about the traumatic event?	0	1	2	3
80. Reliving the traumatic event, acting or feeling as if it were happening again?	0	1	2	3
81. Feeling EMOTIONALLY upset when you were reminded of the traumatic event (for example feeling scared, angry, sad, guilty, etc.)?	0	1	2	3
82. Experiencing PHYSICAL reactions (for example, break out in a sweat, heart beats fast) when you were reminded of the traumatic event?	0	1	2	3
83. Trying not to think about, talk about, or have feelings about the traumatic event?	0	1	2	3
84. Trying to avoid activities, people, or places that remind you of the traumatic event?	0	1	2	3
85. Not being able to remember an important part of the traumatic event?	0	1	2	3
86. Having much less interest or participating much less often in important activities?	0	1	2	3
87. Feeling distant or cut off from people around you?	0	1	2	3
88. Feeling emotionally numb (for example, being unable to cry or unable to have loving feelings)?	0	1	2	3
89. Feeling as if your future plans or hopes will not come true (for example, you will not have a career, marriage, children, or a long life)?	0	1	2	3
90. Having trouble falling or staying asleep?	0	1	2	3
91. Feeling irritable or having fits of anger?	0	1	2	3

92. Having trouble concentrating (for example, drifting in and out of conversations, losing track of a story on television, forgetting what you read)?	0	1	2	3
93. Being overly alert (for example, checking to see who is around you, being uncomfortable with your back to the door, etc.)?	0	1	2	3
94. Being jumpy or easily startled (for example, when someone walks up behind you)?	0	1	2	3

Below is a list of statements about your relationships with family and friends. Please indicate how much you agree or disagree with each statement as being true by making a (X) in the appropriate box.

	Strongly agree	Agree	Disagree	Strongly disagree
95. My friends respect me	3	2	1	0
96. My family cares for me very much	3	2	1	0
97. I am not important to others	3	2	1	0
98. My family holds me in high esteem	3	2	1	0
99. I am well liked	3	2	1	0
100. I can rely on my friends	3	2	1	0
101. I am really admired by my family	3	2	1	0
102. I am respected by other people	3	2	1	0
103. I am loved dearly by my family	3	2	1	0
104. My friends don't care about my welfare	3	2	1	0
105. Members of my family rely on me	3	2	1	0
106. I am held in high esteem	3	2	1	0
107. I can't rely on my family for support	3	2	1	0
108. People admire me	3	2	1	0
109. I feel a strong bond with my friends	3	2	1	0
110. My friends look out for me	3	2	1	0
111. I feel valued by other people	3	2	1	0

112. My family really respects me	3	2	1	0
113. My friends and I are really important to each other	3	2	1	0
114. I feel like I belong	3	2	1	0
115. If I died tomorrow, very few people would miss me	3	2	1	0
116. I don't feel close to members of my family	3	2	1	0
117. My friends and I have done a lot for one another	3	2	1	0

Many patients find it difficult to take their HIV medications exactly as prescribed. Please answer the following questions related to your HIV medication.

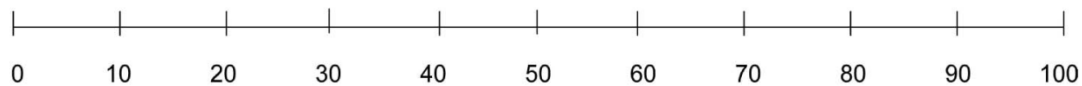
119.

How many doses of your HIV medication did you miss in the last 7 days? _____ doses

120.

Put a mark (X) on the line below at the point that shows your best guess about how much of your prescribed HIV medication you have taken in the last month.

Examples: 0% means you have taken no medication
 50% means you have taken half your medication
 100% means you have taken every single dose of your medication



Please use an (X) to indicate your response for each of the following 4 questions:

121. During the last two weeks, did you forget to take your HIV medications?

☐ YES ☐ NO

122. When you feel better, do you sometimes stop taking your HIV medications?

☐ ALWAYS ☐ SOMETIMES ☐ NEVER

123. Sometimes if you feel worse, do you stop taking your HIV medications?

☐ ALWAYS ☐ SOMETIMES ☐ NEVER

124. Did you forget to take any of your HIV medications over the past weekend?

☐ YES ☐ NO

APPENDIX B: CONSENT FORM

REFERENCE NUMBER: N08/12/354

PRINCIPAL INVESTIGATOR: Adriaan Nel

ADDRESS: Sielkunde
Privaatsak X1
Matieland
7602

CONTACT NUMBER: 083 264 8844

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Committee for Human Research at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

- The study will be conducted at Helderberg Hospital in the Overberg region of the Western Cape. A total of 100 participants will be recruited.
- We are trying to find out to what extent certain factors can influence a patient's ability to adhere to his/her HIV medication. Adhering to one's medication means that you take the correct amounts at the correct times, and that you do not forget to take your medication. This information can help health care workers in assisting their patients to ensure that they adhere to their HIV medication.
- You will be required to complete a form on which you state the details about your personal characteristics, such as your age, gender, race, income level, and so on. You will also have to complete a set of questionnaires and possibly an interview. If there are any questions that you do not fully understand, do not hesitate to ask the researcher to explain it to you.

Why have you been invited to participate?

- As a person living with HIV and taking antiretroviral medication, you can help us to determine what makes it difficult for you to adhere to your HIV medication.

What will your responsibilities be?

- You will have to complete the questionnaires as honestly as possible.

Will you benefit from taking part in this research?

- You have the option of taking juice and cookies after the study. You will receive no money for participating in this study.

Are there in risks involved in your taking part in this research?

- Some of the questions that you will have to answer are may be related to sensitive issues. If you experience any sort of distress as a result of the study, please inform the researcher.

If you do not agree to take part, what alternatives do you have?

- Participation in this study is completely voluntary and you are free to leave at any time. If you do not want to take part, the researcher will still answer any questions you may have.

Who will have access to your medical records?

- The researcher will have access to your medical records. However, the researcher will regard all your information as confidential. In the event that some of this information is used for purposed of academic publication, you will remain anonymous (your name will not be used).

What will happen in the unlikely event that you experience some form of distress as a result of this study?

- You will be referred to a social worker or health care professional within your area.

Are there any costs involved in taking part in the study?

Whether or not you decide to take part, there will be no costs involved for you.

Is there any thing else that you should know or do?

- You can contact the Committee for Human Research at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.
- You can request a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I agree to take part in this research study

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) on (*date*)

.....
Signature of participant

.....
Signature of witness

Declaration by investigator

I (*name*) declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above

- I did not use an interpreter.

Signed at (*place*) on (*date*)

.....
Signature of investigator

.....
Signature of witness